

A Matter of Time:

An Investigation into the Management
of Wait Lists for Breast Cancer
Treatment in Saskatchewan



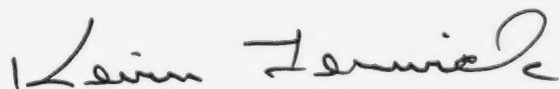
September 2011

The Honourable Don Toth
Speaker of the Legislative Assembly
Province of Saskatchewan
Legislative Building
2405 Legislative Drive
Regina, Saskatchewan
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Dear Mr. Speaker:

It is my honour and privilege to submit, pursuant to Section 30(3) of *The Ombudsman and Children's Advocate Act*, a special report titled *A Matter of Time: An Investigation into the Management of Wait Lists for Breast Cancer Treatment in Saskatchewan*.

Respectfully submitted,



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An Update From the Ombudsman

In May 2009, in response to receiving a complaint, Ombudsman Saskatchewan undertook a review of the Saskatchewan Cancer Agency's (SCA) management of its wait lists and access to treatment for patients diagnosed with Stage I or II breast cancer who required adjuvant chemotherapy. Once the individual case file was completed and resolved in 2010, we shifted our focus to a comprehensive systemic review. That review was completed and provided to the SCA for its review and feedback in March 2011.

The *A Matter of Time* review is a point-in-time study that looked at the SCA's management of its wait lists from 2009 to 2010. The SCA took very seriously the concerns of our complainant (who we have called Mrs. X) and made concerted efforts to change its internal processes and procedures and, consequently, to improve the experience of many women waiting for chemotherapy treatment. A number of these changes also coincided with our final report recommendations.

To a great extent the SCA is a different agency today than the one Mrs. X encountered in 2009. The Agency has made significant changes to its administration, its technology, its processes and its interaction with patients and their families. We have listed a number of these changes in Section 10. A few of those significant changes are highlighted here:

- As of June 2011 the SCA employs a full complement of oncologists and hematologists.
- The Agency has developed multi-disciplinary tumour groups which have adopted benchmarks for treatment and continue to look at improving access to care.
- The Agency has set and will publicly report on five year access targets that will see:
 - 100% of patients contacted within 24 hours of referral.
 - 100% of patients screened for distress.
 - 100% of cases reviewed by a multi-disciplinary team.
 - 100% of patients receive a detailed care plan.
 - 100% of patients assessed for clinical trial eligibility.
 - 90% of new patient referrals seen within 7 days of referral.
 - 90% of patients started on treatment within 14 days of being ready to treat.
 - 90% of patients treated according to published treatment guidelines.
 - 15% of patients enrolled in a clinical trial.

- The Agency has formed a Patient and Family Advisory Council to advise on various SCA matters affecting patients and their families.
- Most importantly, patients who want to know will be provided a time estimate of when they will be able to see an oncologist.

The question that will be and has been asked of Ombudsman Saskatchewan is: if during the course of a review the originating complaints have been resolved, why publicly release the review?

There are several reasons why it is important that our review is publicly released.

First, the Ombudsman is an Independent Officer of the Legislative Assembly. As an independent office, we have a mandate and a duty to publicly report on the work of the office, its recommendations and findings. Publicly releasing special reports of our systemic recommendations is our usual practice, even when many of the recommendations have already been met and implemented.

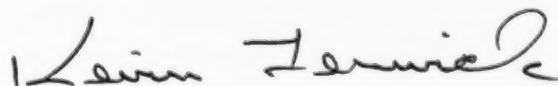
Second, there are other health agencies providing other forms of health care across the province and in other provincial jurisdictions that are struggling with wait times and the concept of fair and equitable access to care. The information examined here may have a broader practical use than just to the Saskatchewan Cancer Agency.

Third, although today the SCA is a different organization than the Agency Mrs. X encountered in 2009, many of the implemented changes, such as having a full complement of oncologists and hematologists, are dependent on factors beyond the control of the Agency. These external factors may change over time and the Agency must be flexible enough to cope under those circumstances.

Finally and most importantly, during the course of this review and as reported in Section 8, we were told in interviews with SCA patients, community advocates and some Agency staff that they believed that in certain cases non-clinical factors could influence where an individual was placed on the wait list. The suggestion that an individual's placement on the wait list could be influenced by non-clinical factors was the most troubling aspect of this review. However, our investigators found no evidence to support that suggestion – not at the time of the review, nor since.

Timely access to and equity of care are basic values of our public health system. The public must have confidence that our health system is fair and equitable, "providing the sickest people with the fastest access to care without compromising access for those whose needs are less urgent but no less real."* That the wait lists in 2009 and in 2010 had not been compromised in the manner suggested to the Ombudsman is vitally important for the general public to know, understand, and accept if confidence in the Agency is to be maintained.

The genesis for many of the changes the SCA has implemented was one woman speaking out about her experience as a breast cancer patient receiving services from the SCA. We sincerely thank her for her willingness to share her story with us. The momentum for the continued improvements that Ombudsman Saskatchewan observes now at the SCA, however, was and is due to the dedication and commitment of the Agency's Board, administration and staff. We thank them for their cooperation during the course of this review.



Kevin Fenwick, Q.C.
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*Health Council of Canada (2005). *A Background Note on Benchmarks for Wait Times*, November 2005. Ottawa: Health Council of Canada at 1, as cited in B. Postl (2006). *Final Report of the Federal Advisor on Wait times*. Ottawa: Health Canada at 18. Website: <http://www.hc-sc.gc.ca/hcs-sss/pubs/system-regime/2006-wait-attente/index-eng.php>.

Executive Summary

Part One: Waiting for Care

Section 1: Report Overview

Wait times in health care have become an increasingly important issue for many Canadians and consequently, for government. People want to feel confident that health care services will be available to them if and when they are needed and they want a health care system that is fair and equitable. Timely access and equity of care are basic values of our public health care system. However, waiting for care, and ultimately wait lists, are a current reality. Wait times have become the measure used by many in the public, the media, and in government to judge the effectiveness of the health care system.

In May of 2009, Ombudsman Saskatchewan was approached by a Saskatchewan resident (referred to here as Mrs. X) who had been diagnosed with, and undergone treatment for, breast cancer. Mrs. X was not concerned about the actual clinical care she received from the provincial health care system and specifically the Saskatchewan Cancer Agency (SCA). Rather, she was concerned with what she perceived to be barriers to accessing

timely care, specifically chemotherapy, and her experience while waiting for care. Ombudsman Saskatchewan undertook a review of the Saskatchewan Cancer Agency's management of its wait lists and access to treatment for patients diagnosed with Stage I or II breast cancer who required a treatment pathway involving surgery and adjuvant chemotherapy.

In Canada and in Saskatchewan, breast cancer is one of the most commonly diagnosed cancers among women. Each year more Canadian and Saskatchewan women are being diagnosed with breast cancer, are living with breast cancer, and are surviving breast cancer. While men can also be diagnosed with breast cancer, the illness is far more prevalent in women. For ease and convenience in this report, we will use feminine terms, but we intend the report and our discussion of services and improvements to apply equally to all patients referred to the SCA with breast cancer, regardless of gender.

The Scope and Purpose of the Review

When we began this review, we were conscious of the fact that we could not review the clinical decisions made with respect to oncology services provided by the SCA and the medical professionals who make these decisions. Ombudsman Saskatchewan does not have the jurisdiction to do so, nor do we have the expertise

to review those clinical decisions. In addition, the concerns brought forward were not related to the clinical decisions or services provided by the SCA. Our review concentrated on the Agency's management of the wait lists for oncology services and the administrative decisions made therein. We focused on the policies and procedures that guide those administrative decisions and looked at the process from the point of referral through to the first chemotherapy treatment. We also reviewed the information and support provided by the SCA to women who embark on this process.

The Evaluative Framework and Methodology of the Review

In order to facilitate this review, we developed an evaluative framework based on the principles of care found in Dagnone's *For Patients' Sake* review (2009); also referred to as the *Patient First Review*. The principles of Patient and Family Centred Care (PFCC) outlined by Commissioner Dagnone are similar to and at times overlap with the attributes of fair practice as described by Ombudsman Saskatchewan. For this review, we combined the attributes of fair practice with the principles of PFCC.

We identified key evaluative questions that looked at the SCA's organizational and administrative structures, policies, and procedures that supported the wait lists for oncology services and the patient experience while on a wait list. These questions were developed based on the assumption that wait lists, given their purpose, are or should be patient-centred. The methods used to carry out this review included:

- literature and legislative reviews.
- review of SCA documents including policies and procedures and

information provided to patients diagnosed with breast cancer who are registered on the wait list.

- review and analysis of prior evaluation reports and their recommendations.
- key personnel interviews.

Section 2: Treatment Overview

The treatment of breast cancer depends on various patient-centred, system, and environmental factors and may take many forms. Surgery is a common primary therapy used to treat breast cancer. There are times when other forms of therapies are needed in addition to the surgery. When several therapies are used in combination with one another they can be given together or at different times depending on the type and stage of cancer. A therapy such as chemotherapy or radiation, given after the primary treatment to control the spread of the cancer and destroy any remaining cancer cells is called adjuvant therapy. This review focused on one treatment pathway: surgery followed by adjuvant chemotherapy. In particular, this review focused on the care intervals involved in the clinical care pathway from referral to a cancer care agency to first adjuvant therapy.

Section 3: Guidelines and Benchmarks

Clinical Practice Guidelines

Clinical practice guidelines for the treatment and management of breast cancer in Canada were developed in the early 1990's. These guidelines provide and promote an evidence-based summary of best practices and are intended to ensure consistency of breast cancer care. A number of the clinical guidelines discuss the optimal time period in which a procedure should be provided to the majority of patients. These time periods have also been referred to as benchmarks.

Saskatchewan has established targets for certain diagnostic and treatment procedures in the care and management of breast cancer. The SCA has informally accepted the adjuvant chemotherapy benchmark of 12 weeks established by a clinical study conducted in the province of British Columbia. While the 12 week interval is being used as an informal benchmark, it has not been formally adopted and a provincial target has not been developed to gauge the SCA's performance in meeting the benchmark.

The System's Impact on Wait Times, Benchmarks, and Ability to Meet the Targets

Wait times are influenced not only by patient-centred factors, but also environmental and system factors. These factors can include, but are not restricted to, the availability of oncologists and nursing staff, the availability of equipment, the capacity of the SCA to provide services,

and more generally, the financial resources provided to the SCA to fulfill its overall mandate. In addition to these factors, the administrative structures in place to support the wait lists and the processes used to manage them must also be considered. How individuals are "managed" while on the wait list can also influence their perceptions as to whether or not they are receiving timely care.

Section 4: The Saskatchewan Cancer Agency and Its Wait List Process

The SCA operates two cancer centres, the Allan Blair Cancer Centre (ABCC) and the Saskatoon Cancer Centre (SCC).¹ At the time of this review, the cancer centres were managed as separate entities and each centre independently accepted its own patient referrals, prioritized its own patients, and managed its own wait lists for cancer treatments and services.

The process used by the referral centre staff to manage patients through the wait list is intricate and complex. Once diagnosed with cancer, a woman is referred to the SCA by a doctor in the community. Patients receive an information package and are contacted by the cancer centre's Patient Access Coordinator who acts as a quasi-system navigator until the patient's first appointment with an oncologist.

The length of time a woman will wait to see an oncologist depends on patient-centred factors as well as organizational factors. While the woman is waiting for an appointment, a number of tasks

occur internally at the cancer centre that moves the woman forward on a wait list. Managing and supporting the wait list is an administrative process that organizes the delivery of needed medical services to a targeted population. For new patients, a patient file or chart is created and the type of appointment the patient will require – a new patient appointment or a review appointment – is determined. All patients waiting for new patient appointments to be scheduled are placed on the wait list.

Triage of Patient Files

Once the chart moves from initial referral and the patient is placed on the wait list, the chart is then passed over to clinical staff for triaging. Triage is a clinical term that for the purposes of this review indicates that a clinical professional is reviewing a patient's chart in order to sort it, determine what type of treatment the patient requires, and determine how quickly the patient requires that treatment.

There are two different types of triaging that occur (referred to here as initial triage and medical triaging), and each is completed by separate clinical staff for different purposes. Often, both initial and medical triaging of a chart occurs simultaneously, or are completed closely together. The initial triage is completed by a registered nurse from the referral centre and the purpose is to sort the charts by the type of treatment that the patient requires and the urgency of the matter. The appropriate oncologist will also medically triage the chart, separately from the nurse. In the medical triage, the oncologist reviews the chart for any important information, to order any outstanding images or lab work that an oncologist will need at the patient's first appointment, and to create a prioritization list of patient charts.

Based on the priority of the wait list established by the oncologists triaging the charts, a nurse assigns next available appointments. If there are two charts with an equal priority ranking, the nurse assigns the next available appointments based on which patient was first medically ready to be seen. While a chart is on the wait list, it will be reviewed several times by both the nurse and oncologist. This means that when circumstances change, the patient's priority ranking should change as well. As the case remains on the wait list, it is continually monitored to ensure women are seen within the twelve week benchmark whenever possible. Another duty of the nurse is to assess whether the patient is medically ready to be seen. If the patient is ready to be seen, the nurse enters the "ready to see" (RTS) date into the centre's computer system. If the patient is not ready to be seen, then the case is on hold until the patient is ready to be seen. The nurse notes in the comments section of the wait list information the reasons why the patient is not ready to be seen, and the case is continually monitored.

Scheduling First Appointments with an Oncologist

For the actual scheduling of appointments, a nurse generates reports in two different computer systems. The "New Patient Slot Report" lists all of the oncologists and their available appointment slots for each upcoming week. The "Waitlist Custom Report" is the tool from which appointments are booked. Although the reports are generated by a computerized program, much of the work in managing the lists between report runs is completed manually. Using these reports, the nurse assigns patients who are ready to be seen and who are in order of priority next on the wait list to any available new patient appointment

slots. The nurse manually writes the appointment time in the patient's chart and on the two generated reports.

Once a first appointment with an oncologist has been scheduled, the nurse provides the chart to an administrative staff person who ensures the chart is complete and notifies the patient about her appointment. The patient's name is then removed from the centre's computerized wait list.

Information Provided to a Patient While She Waits

Historically, patients were not told there was a wait list or that they were on it. This has changed in the last two years. Now patients are advised that there is a wait list; that they are on the wait list; how many people are on the wait list; and, on average, how many new people are added to the wait list each month. At the time of our review, patients were not provided information on where they fell on the wait list or how long, approximately, they might expect to wait. The SCA feels that there are too many variables affecting its ability to make proper estimates of when an individual will see an oncologist. SCA staff interviewed for this report stated that they worry that if the estimate is incorrect, it will cause more stress and anxiety for the patient than receiving no estimate.

Part Two: Findings and Recommendations

Section 5: Capacity

Operational Capacity at the SCA

Staff interviews revealed concerns about limited resources and how at times the demand for services outweighs the Agency's capacity to meet that demand. Various external and internal factors impact the Agency's ability to provide services. However, the SCA has an obligation to provide equitable and timely access to all patients, both under PFCC principles and in order to be fair. Managing the Agency's capacity involves managing its limited resources and the Agency's processes, including the wait list process.

Managing Its Staffing Resources

Many of the staff interviewed reported that the difficulty in effectively managing its wait list was due to a lack of qualified medical oncologists to meet the demand for its services. According to the SCA, at the time of the review it was having difficulty attracting and recruiting qualified medical oncologists partly due to the worldwide demand for medical oncologists but also because of the lack of incentives for attracting candidates. The Ombudsman agrees that the lack of trained oncologists can contribute to delays in care.

Furthermore, increasing the workloads of already overloaded physicians is likely to lead to further recruitment and retention

issues within the SCA and may actually further decrease its capacity over time.

In other areas however, the process does not always maximize the skill sets of Agency clinical staff. Some of the tasks assigned to referral centre nurses in moving a case from point of referral to first appointment with an oncologist are administrative and can be completed by a properly trained administrative support staff person. In addition, some information provided to patients by the oncologist in their first appointment could be provided earlier in the process, and by nursing staff.

Recommendation 1

The SCA review the administrative processes involved in managing the wait list from point of referral to the first consultation/appointment with an oncologist to ensure the skill sets of every member of its clinical staff are fully maximized.

Clinical Benchmarks and Access Targets

At the time of the review, the SCA did not have a publicized benchmark for adjuvant chemotherapy for women diagnosed with breast cancer; however it has informally accepted the benchmark established by a study conducted in the province of British Columbia. Benchmarks can provide patients with an understanding of the time frames for particular treatments and they can be used to judge how effective the SCA and the provincial health system is in providing services in comparison to other jurisdictions.

Recommendation 2

The SCA consider formally adopting its informal benchmark for adjuvant chemotherapy for breast cancer patients and develop clinically appropriate access targets.

Section 6: Managing the Wait List

Factors That Influence Wait Times

Waiting for health care services may be necessary because of the overall treatment plan or because of operational capacity and capacity management. Once a clinical decision has been made that a particular treatment is necessary, how, when, and where a woman will access those services may depend on system and organizational factors that are beyond the patient's control. It was found that these larger system and Agency factors were having a negative impact on managing cases from point of referral to initiation of oncology treatment.

One Provincial Wait List

At the time of this review, each referral centre maintains its own wait list and the SCA monitors overall waits provincially to ensure equity of access between the centres. This process appears to be administratively inefficient due to the required duplication of work. Merging the two separate lists into one provincial wait list would likely make it easier for the SCA to ensure equal access for all Saskatchewan residents based on the

care they require. A functioning "e-health" system that would link the two cancer centres would be necessary.

Recommendation 3

The SCA merge its two wait lists to one provincial list that is centrally managed and supported.

The Structure and Administration of the Wait Lists

The SCA's two wait lists include a "patchwork" of information entered and stored in computer systems and on manually generated paper lists. The information systems are inefficient as they add unnecessary duplication of work and complexity to the process. The more complicated and multi-step the process, the more opportunities arise for errors and consequent delay. This is not an efficient way to manage the gateway for an essential health care service.

Recommendation 3 (repeated)

The SCA merge its two wait lists to one provincial list that is centrally managed and supported.

Fragmented Oversight

The Ombudsman investigators were advised by SCA staff that there is no one staff person responsible for maintaining or overseeing the wait lists, ensuring the lists are current, and ensuring that patients are being seen in a timely manner. Overall, we found a lack of ownership of the wait lists and both clinical and administrative staff expressed

their confusion as to who among them were "actually responsible" for the wait lists.

Recommendation 4

The SCA appoint a senior staff member to be responsible for overseeing the entire wait list for the province, which includes ensuring its integrity, that it is maintained efficiently, that new patients are added quickly, and that all patients receive timely appointments.

Section 7: Information Infrastructure and Supportive Technology at the SCA

State at the Time of Our Review

The lack of a functioning e-health system to link the two cancer centres at the time of the review was viewed by SCA staff as being responsible for a number of the inefficiencies with the wait lists. While the limited technology is a problem, technology alone will not solve the resource capacity and efficiency issues of the cancer centres.

Information Technology

However, appropriate technology is needed to manage the SCA's wait lists and facilitate the movement of a case from initial referral to first appointment with an oncologist. Appropriate technology is also needed to address the data gaps that occur when information produced by external sources

cannot be properly captured and stored in the wait lists.

Recommendation 5

The SCA review and evaluate its information and communication technology on an ongoing basis or as needed to ensure the technology can adequately and effectively support the provision of cancer care services.

Recommendation 6

The SCA consider introducing complete and comprehensive electronic medical records to form the basis for the provincial patient wait list.

Data Collection – Measuring Factors that Affect Wait Times

Ombudsman investigators were told that patients on the wait list were not provided with timeframes or estimates of when they may be seen by an oncologist. SCA staff reported that this was due to the generalist nature of the Agency's oncology services. However, it appears the SCA also did not have the appropriate technology to adequately measure the time it takes for patients to be seen. The Agency has now started tracking referral patterns and doing so has produced some positive results. During our review, Ombudsman Saskatchewan investigators also learned that until recently the SCA did not uniformly or consistently track the number of patients any one oncologist had on his or her caseload at any given time. Actual caseloads of physicians are now

being tracked and improved measurements are being gathered and kept in terms of resource utilization and capacity.

Recommendation 7

The SCA develop measurement tools that will assist it in tracking what patient-centred and system-centred factors influence timely and equitable access to care. Such measures should be able to provide the Agency with information to systemically manage its resources, and also to provide information to individual patients about where they are on the wait list and when they can reasonably expect to be seen by a medical oncologist.

Posting Wait Times Online

The SCA publishes information about wait times for chemotherapy on its website, however, the information provided is limited in that it does not provide actual wait times for an initial consult with an oncologist and the initiation of chemotherapy, or actual wait times at the ABCC or the SCC. Information about wait times should be made public and should be as detailed as possible to allow patients the ability to make informed choices with their primary care physician about available treatment options including the possibility of out-of-province care.

Recommendation 8

We support and repeat the recommendation made in an operational review conducted by RockBank Consulting in 2006: "Ensuring that the SCA web site has protocols, guidelines, resources and links needed to support patients and families along the full cancer journey."

Section 8: Communication and Navigation Assistance

Effective Communication

The primary issue raised in the original 2009 complaint to Ombudsman Saskatchewan involved a lack of information and effective communication between the SCA and a patient waiting to access cancer treatment. Effective communication is a cornerstone of a PFCC health system, especially in the principles of informative care and respectful care, as PFCC requires that patients be active participants on their medical care team and in all decisions made about their medical care. In order for patients and their families to participate in health care decisions, they need to be fully informed about their illness and treatment options in a timely manner. Effective communication also increases public confidence in the Agency. We were told in interviews with SCA patients, community advocates and some Agency staff that they believed that in certain cases non-clinical factors could influence where

an individual was placed on the wait list. However, our investigators found no evidence to support that suggestion – not at the time of the review, nor since.

Communication Between the SCA and Community Doctors

This review also found communication and information sharing issues between the SCA and the broader health sector. Some community doctors were unclear about their role, the SCA's processes, what the SCA requires of them, and how to ensure good care for their patients. In a truly patient-centred system, the SCA and referring doctors should act in a highly collaborative manner to ensure that patient care is seamless, continuous, and convenient to the patient.

Specific areas where information appeared to be lacking include out-of-province treatment options and referrals and triage. The expectation of the SCA is that the community doctor will discuss all treatment options directly with the patient and that these options will include a referral to one of the SCA's cancer centres or out-of-province depending on the patient's needs and personal preference. It is not clear, however, whether all community doctors understand this expectation or have adequate information about the SCA capacity which may influence whether or not they refer their patient out-of-province. Many community doctors are unsure about the SCA's triage process, referral guidelines, and how urgent patients are handled. This can lead to improper or incomplete referrals. If community doctors are provided with a better understanding of the process and of the Agency's referral expectations, it will assist them in providing the Agency with appropriate and complete referrals, thus saving Agency resources.

Recommendation 9

The SCA review RockBank Consulting's report and give consideration to implementing the noted recommendation, "A shift in care to the most appropriate provider, e.g. moving some care back to the community and to family physicians, partnering with other providers, such as advanced practice nurses and clinical associates."

Recommendation 12

If it has not already done so, the SCA develop information for community doctors to provide to patients they are referring to the SCA. This should include information about the wait list and the expected time period an individual should remain on the wait list and when patients can be expected to be referred back for follow-up care with their community doctor.

Recommendation 10

In situations where the SCA finds itself unable to adequately address the demand for its services, the Agency provide all referring community doctors sufficient information to allow the referring doctors and their patients to make informed decisions about alternative care plans at other cancer centres, including agencies outside the province.

Recommendation 11

The SCA develop a plan for consultation and use that plan to consult with community doctors to determine what information is required to be exchanged between health care providers in order to facilitate robust referrals.

Communicating with Patients

Within a truly PFCC system, patients and their health care providers are partners in a collaborative team jointly making health care decisions. Communication is important as patients need to be informed, and health care providers need to be cognizant of their patients' needs and how those needs may be met. Information that should be provided to patients includes an estimated timeframe to see an oncologist. At the time of this review the SCA did not provide this type of information. While improvements have been made in terms of information provided to patients, at the time of our review they were still not able to provide an estimate to patients of when they will be seen by a medical oncologist.

Recommendation 13

When requested, the SCA provide estimates to patients of when they will be seen by a medical oncologist. If an estimate is unable to be met, the SCA should inform the patient, provide an explanation, and provide a new estimate.

Navigational Assistance

Many patients require information about the care pathway and how to navigate it. All patients are unique in their needs and as such, different patients will require different information of varying levels of complexity and at different times. System navigators are a way to provide an individual patient with the information they may need or want. System navigators are individuals who work within or with the health care system and who act as a "personal guide" to patients and their families. System navigators provide general support and assistance to patients which may include providing information, answering questions, identifying options for treatment and other support services, and acting as an advocate for patients when necessary. While each of the cancer centres has a Patient Access Coordinator (PAC) who assists patients, the PAC is not a true system navigator.

Recommendation 14

The SCA ensure navigational assistance is in place to assist patients who are waiting for a first appointment with an oncologist.

In it Together – Partnerships Between the SCA and its Patients

The SCA administrative process to manage the wait list appears to have developed over time, and is primarily focused on the organizational needs of the Agency. At the time of our review individual patients had no involvement in any decisions about how their case was managed until they saw

an oncologist. Patients at the time of our review were not provided with adequate information about the wait list and their placement on the list. To the Ombudsman's knowledge, patients are not involved in the oversight or evaluation of the wait list process. For the SCA to move firmly from its traditional roots to a PFCC system it needs to become patient-centred in all aspects of care, including how that care is organized, administered, and delivered. The SCA can begin this process by introducing a patient charter.

Recommendation 15

Working in partnership, the SCA, its patients and patient advocacy groups develop and introduce a patient charter based on the principles of PFCC.

Section 9: A Change in the Organizational Environment

The Environment of the SCA

Concerns about the organizational culture or environment within the SCA have been long standing and highlighted in previous reports. Cultural issues can at times spill over into the community and the Agency's relationship with the larger community. The organizational culture of the SCA requires a significant shift if the Agency is to successfully move to a Patient and Family Centred model of care. While some of these concerns were raised by SCA staff during interviews with Ombudsman investigators,

Recommendation 9

The SCA review RockBank Consulting's report and give consideration to implementing the noted recommendation, "A shift in care to the most appropriate provider, e.g. moving some care back to the community and to family physicians, partnering with other providers, such as advanced practice nurses and clinical associates."

Recommendation 10

In situations where the SCA finds itself unable to adequately address the demand for its services, the Agency provide all referring community doctors sufficient information to allow the referring doctors and their patients to make informed decisions about alternative care plans at other cancer centres, including agencies outside the province.

Recommendation 11

The SCA develop a plan for consultation and use that plan to consult with community doctors to determine what information is required to be exchanged between health care providers in order to facilitate robust referrals.

Recommendation 12

If it has not already done so, the SCA develop information for community doctors to provide to patients they are referring to the SCA. This should include information about the wait list and the expected time period an individual should remain on the wait list and when patients can be expected to be referred back for follow-up care with their community doctor.

Communicating with Patients

Within a truly PFCC system, patients and their health care providers are partners in a collaborative team jointly making health care decisions. Communication is important as patients need to be informed, and health care providers need to be cognizant of their patients' needs and how those needs may be met. Information that should be provided to patients includes an estimated timeframe to see an oncologist. At the time of this review the SCA did not provide this type of information. While improvements have been made in terms of information provided to patients, at the time of our review they were still not able to provide an estimate to patients of when they will be seen by a medical oncologist.

Recommendation 13

When requested, the SCA provide estimates to patients of when they will be seen by a medical oncologist. If an estimate is unable to be met, the SCA should inform the patient, provide an explanation, and provide a new estimate.

Navigational Assistance

Many patients require information about the care pathway and how to navigate it. All patients are unique in their needs and as such, different patients will require different information of varying levels of complexity and at different times. System navigators are a way to provide an individual patient with the information they may need or want. System navigators are individuals who work within or with the health care system and who act as a "personal guide" to patients and their families. System navigators provide general support and assistance to patients which may include providing information, answering questions, identifying options for treatment and other support services, and acting as an advocate for patients when necessary. While each of the cancer centres has a Patient Access Coordinator (PAC) who assists patients, the PAC is not a true system navigator.

Recommendation 14

The SCA ensure navigational assistance is in place to assist patients who are waiting for a first appointment with an oncologist.

In it Together – Partnerships Between the SCA and its Patients

The SCA administrative process to manage the wait list appears to have developed over time, and is primarily focused on the organizational needs of the Agency. At the time of our review individual patients had no involvement in any decisions about how their case was managed until they saw

an oncologist. Patients at the time of our review were not provided with adequate information about the wait list and their placement on the list. To the Ombudsman's knowledge, patients are not involved in the oversight or evaluation of the wait list process. For the SCA to move firmly from its traditional roots to a PFCC system it needs to become patient-centred in all aspects of care, including how that care is organized, administered, and delivered. The SCA can begin this process by introducing a patient charter.

Recommendation 15

Working in partnership, the SCA, its patients and patient advocacy groups develop and introduce a patient charter based on the principles of PFCC.

Section 9: A Change in the Organizational Environment

The Environment of the SCA

Concerns about the organizational culture or environment within the SCA have been long standing and highlighted in previous reports. Cultural issues can at times spill over into the community and the Agency's relationship with the larger community. The organizational culture of the SCA requires a significant shift if the Agency is to successfully move to a Patient and Family Centred model of care. While some of these concerns were raised by SCA staff during interviews with Ombudsman investigators,

it was unclear whether these concerns had any impact on patients' access to services at the Agency. In addition, since 2009, the SCA has undergone a number of changes, including changes in its management personnel.

The Complexity of Accessing Care

Ombudsman Saskatchewan did identify one issue with respect to the environment that directly impacted the Agency's ability to fully understand and address issues concerning the wait lists, the management of the lists, and ultimately a woman's access to cancer treatment. Specifically, it was found that the administrative process used by the SCA to manage patients' access to cancer care services is unduly complicated. The complexity of the process acts as an impediment to change. There is a need to simplify the process and make it more accessible to patients, families, and other health care partners, including referring physicians. It is the responsibility of those within the SCA to ensure that the process is not unduly complicated and to adequately communicate the process in an understandable form.

Recommendation 16

The SCA review its administrative processes connected to the wait list on an ongoing basis, with the goal to streamline and simplify the processes.

Part Three: SCA Response

Section 10: Changes Made at the SCA Since This Review

Progress Since Our Review

The review of the SCA's wait list process began in 2009 with an investigation of the individual complaint. As is our policy, once the individual case file was completed and resolved in 2010, Ombudsman Saskatchewan began a comprehensive systemic review. The SCA has been fully cooperative with our review and we thank them for their cooperation and professionalism. Since Ombudsman Saskatchewan began this review, the SCA has continued to work to improve its processes and access to its services.

Since we began our review, the SCA has made several changes to its leadership, its administration, its technology, and its processes. The Agency has made a concerted effort to become patient and family centred and has formed a Patient and Family Advisory Council who advise on various SCA matters as well as made various other significant improvements. Ombudsman Saskatchewan acknowledges the efforts and progress of the Agency. While there is still work that the Agency will need to undertake in order to fully meet all of the recommendations made in this report and to continue striving for quality improvement, the changes that the SCA has implemented appear to be positive

and will likely take it a significant distance towards the end goal of having all patients of the Agency receive accessible, timely, and appropriate treatment provided in a respectful manner.

A Matter of Time:
An Investigation into the
Management of Wait Lists for
Breast Cancer Treatment in
Saskatchewan

Part 1

Waiting
for Care

Section 1

Breast Cancer Wait List Systemic Investigation

1.0 The Issue: Waiting for Care

Wait times in health care have become an increasingly important issue for many Canadians and consequently, for government. People want to feel confident that health care services will be available to them if and when they are needed and, "within a time frame that does not significantly alter their health or well-being."² People also want a health care system that is fair and equitable, "providing the sickest people with the fastest access to care without compromising access for those whose needs are less urgent but no less real."³ Wait times have become the measure used by many in the public, the media, and in government to judge the effectiveness of the health care system.⁴

Waiting too long for care can negatively impact an individual's physical and psychological health as well as affect their ability to function on a daily basis.⁵ Wait times can also have an impact on the performance of the health care system. Beyond the obvious administrative costs involved in creating and managing wait lists, there can be additional costs related to treatment complications that may arise because someone was waiting too long for care.⁶ Stories of individuals waiting too long for health care may also erode public confidence in the system.

Waiting for care is never easy, whether the care is to address a fairly routine health matter, or a fairly serious illness. When an individual receives a necessary health care service, they may find the care to be excellent, but waiting for that care may prove to be disconcerting and anxiety-provoking. In May of 2009, Ombudsman Saskatchewan was approached by a Saskatchewan resident (referred to here as Mrs. X) who had been diagnosed with, and undergone treatment for, breast cancer.⁷ Mrs. X was not concerned about the actual clinical care she received from the provincial health care system and specifically the Saskatchewan Cancer Agency (SCA). Rather, she was concerned with what she perceived to be barriers to accessing timely care, specifically chemotherapy, and her experience while waiting for care.

Timely access to and equity of care are basic values of our public health care system. However, waiting for care, and ultimately wait lists, are a current reality. Given the finite resources of our health care system, "it is safe to predict that there will always be a gap between the demand for health-care services and the resources available to provide them."⁸ How these gaps are managed, how wait lists are administered, and how individuals are treated while waiting for care are as critical to the individual as the actual clinical services received.

At the time of our review the SCA maintained separate wait lists at each of its cancer centres where all Saskatchewan residents diagnosed with various forms of cancer were queued for both systemic oncology and radiation therapy services. Given the complaint that came forward and the harsh reality that breast cancer is the most frequently diagnosed cancer among Canadian and Saskatchewan women,⁹ the Ombudsman limited his review to the SCA's administration of its wait lists for those individuals who had been diagnosed with early stage breast cancer and who required adjuvant chemotherapy following surgery.

On May 20, 2009, the Ombudsman provided notice to both the Minister of Health and the SCA of his intention to review the administration of the wait lists for oncology services, specifically adjuvant chemotherapy, for women diagnosed with early stage breast cancer.

1.1 The Purpose of the Review

The SCA provides cancer education, screening, and treatment (specifically chemotherapy and radiation therapy services), throughout the province and operates two cancer centres: the Allan Blair Cancer Centre (ABCC) in Regina and the Saskatoon Cancer Centre (SCC). Once referred to the SCA by either a family doctor or surgeon, the woman is "registered" and placed on a wait list to access SCA services.¹⁰ The SCA is both the administrator of the wait lists and the clinical service provider for all radiation therapy and chemotherapy.

When we began this review, we were conscious of the fact that we could not

review the clinical decisions made with respect to oncology services provided by the SCA and the medical professionals who make these decisions. Ombudsman Saskatchewan does not have the jurisdiction to do so, nor do we have the expertise to review those clinical decisions. In addition, the concerns brought forward were not related to the clinical decisions or services provided by the SCA. Our review concentrated on the Agency's management of the wait lists for oncology services and the administrative decisions made therein. We focused on the policies and procedures that guide those administrative decisions and looked at the process from the point of referral through to the first chemotherapy treatment. We also reviewed the information and support provided by the SCA to women who embark on this process.

1.2 The Evaluative Framework and Methodology of the Review

In order to facilitate this review, we developed an evaluative framework based on the principles of care found in Dagnone's *For Patients' Sake* review (2009); also referred to as the *Patients First Review*. We chose the *For Patients' Sake* review because it was the most recent comprehensive review of the provincial health care system that had far-reaching input from consumers of the services (patients), government, and health care providers. Its final report recommended a shift from the traditional public health care system in the province of Saskatchewan to a patient first system, one based on the principles and theories of Patient and Family

Centred Care (PFCC).¹¹ In addition, the recommendations made were accepted by government.

In his report, Commissioner Dagnone made 16 recommendations for improving the patient experience and system performance. Some of these recommendations were directed at the services provided by the SCA. Commissioner Dagnone recommended a cultural shift in order to embed "Patient First" as a core value for this highly valued, public system. In such a system, health care would be,

1. Equitable – Patients would receive the care they need, when they need it, regardless of factors such as address, age, and ability to pay out of pocket.
2. Coordinated and Timely – Patients would receive seamless, coordinated, and continuous care across health regions, facilities, units, programs, and disciplines. Artificial boundaries, whether in geography, provider specialty, or program focus would not create silos or barriers for patients and their families. Patients would not face waits that add to their pain and suffering, or their expense (e.g., multiple trips and visits). Patients would not be asked to repeatedly share the same information, as they move across artificial boundaries.
3. Informative – Patients and families would be informed as to the factors affecting their health and the options available to them. Doctors, nurses and other providers and treatment staff would take time to listen and explain.
4. Respectful and Comprehensive – Patients and providers would engage in respectful partnerships, where fears and hopes would be heard and understood. Patients would be treated

as whole people, not parts, and care providers would be empowered to consider all of a patient's concerns.¹²

The principles of PFCC outlined by Commissioner Dagnone are similar to and at times overlap with the attributes of fair practice as described by Ombudsman Saskatchewan. For this review, we combined the attributes of fair practice with the principles of PFCC.

We identified key evaluative questions that looked at the SCA's organizational and administrative structures, policies, and procedures that supported the wait lists for oncology services and the patient experience while on a wait list. These questions were developed based on the assumption that wait lists, given their purpose, are or should be patient-centred.

We then mapped the wait list process from first referral to the SCA to first oncology appointment. Again, we were not reviewing clinical decisions but only administrative decisions. To differentiate between the two types of decisions, we developed working definitions of what is a clinical decision and what is an administrative decision in the management of a wait list in a health care setting.

Prior to our review, the SCA had completed two internal reviews: *the Saskatchewan Cancer Agency Clinical Service Directional Plan* (2006),¹³ and *Improving Access to Cancer Care Phase One Report* (2007).¹⁴ These two reports were commissioned by the SCA and separately examined both clinical and administrative issues related to cancer care, including oncology services. Both made a series of recommendations. We used these two reports as a starting point for our analysis and we adopted many of the recommendations made by the respective authors.

In summary, for this review we completed:

- A comprehensive literature review examining PFCC theory and principles, health care wait list scheduling theories, wait lists in the Canadian health care system, clinical treatment guidelines for breast cancer in Canada, New Zealand, and Great Britain, clinical benchmarks for adjuvant chemotherapy and radiation therapy, the etiology and treatment of breast cancer, and the prevalence and incidence of rates of breast cancer in Canada, in Saskatchewan, and in under-served populations.
- A review and analysis of provincial legislation and regulations on the provision of cancer care services in Saskatchewan, including *The Cancer Agency Act* and its related Regulations.
- A review and analysis of SCA documents, including policies and procedures, committee minutes, and internal correspondence related to patient care and the management of the wait lists for radiation and systemic treatment.
- A review and analysis of several evaluation reports commissioned by the SCA between 2006 and 2009 on the administration and provision of clinical services by the Agency.
- A review of all information produced by the SCA and provided to patients diagnosed with breast cancer who are registered on the wait list.
- Interviews with SCA personnel, including Referral Office staff, staff of the Quality of Care Coordinator program, staff of the Patient Access Coordinator program, the Site Manager for Out-Patient Services at the ABCC, the Head of Medical Oncology at the ABCC, both Vice-Presidents of Care Services for the SCA, and the Program and Policy Consultant for the SCA.
- Interviews with cancer patients and their families, cancer care advocates, and personnel from the Canadian Cancer Society, and the Health Quality Council of Saskatchewan.
- Interviews with key personnel from the Ministry of Health Provincial Quality of Care program.

Section 2

An Overview of Breast Cancer

2.0 Incidence, Prevalence, and Survival Rates

In Canada and in Saskatchewan, breast cancer¹⁵ is one of the most commonly diagnosed cancers¹⁶ among women.¹⁷

Each year more Canadian and Saskatchewan women are being diagnosed with breast cancer, are living with breast cancer, and are surviving from breast cancer. This will result in a growing demand for health care and related social support services.¹⁸

In Canada

- On average, 445 Canadian women are diagnosed with breast cancer every week.
- On average, 100 Canadian women die of breast cancer every week.
- One in nine Canadian women (11%) are expected to develop breast cancer during their lifetimes. (This means by age 90.)

(Source: Canadian Breast Cancer Foundation)

In Saskatchewan in 2010

- It is estimated that 630 women were diagnosed with breast cancer.
- It is estimated that 160 women will die of breast cancer.

(Source: The Canadian Cancer Society)

Surviving Cancer

- Since the mid 1980's the relative survival rate (RSR) for women with breast cancer has steadily increased.
- The relative survival rate (RSR) for women with breast cancer at 1, 3, 5 and 10 year-period after treatment was reported to be 97.2%, 91.9%, 87.5% and 79.7% respectively.

(Source: L.F. Ellison & L. Gibbons (2006), "Survival from cancer-up-to-date predictions using period analysis." *Health Reports*, 17(2), Statistics Canada)

2.1 Treatment Overview

Although breast cancer is one of the most common forms of cancer diagnosed in women, it is not a "single condition" with a corresponding single method of treatment.¹⁹ Breast cancer care is complex and its treatment will be dependent upon a number of patient-centred factors including the type, stage, and grade of the tumour, type of surgery and treatment therapies required, and the presence of other risk factors including age, ethnicity, lifestyle, and family history of cancer.²⁰ In conjunction with the patient-centred factors, other system and environmental factors can impact treatment, including the availability of medical staff, distance to treatment centre, and the resource capacity of the cancer care agency and the health care system in general.

Once diagnosed, a woman's treatment plan is developed based on the type, stage, and grade of the breast cancer, the individual's overall health and sensitivity to hormones, and her personal situation and preferences. Treatment plans can include one form of therapy – often called the primary treatment – or several forms or types of therapies. There are typically three main cancer treatments—surgery, radiation therapy, and chemotherapy.²¹ One of, if not the most common primary therapy used to treat breast cancer is surgical intervention.

There are times when other forms of therapies are needed in addition to the surgery. When several therapies are used in combination with one another they can be given together or at different times depending on the type and stage of cancer.²² A therapy, such as radiation or chemotherapy, given before the primary treatment to shrink the tumour is called

neoadjuvant therapy.²³ Therapies such as chemotherapy, radiation, hormone or biological therapies, or a combination thereof, given after the primary treatment to control the spread of the cancer and destroy any remaining cancer cells are called adjuvant therapy.²⁴

For the purposes of this review, our focus will be on one treatment pathway: surgery followed by adjuvant chemotherapy.

2.2 Clinical Care Pathways

Breast cancer care is typically, "characterized by a sequence of events along a pathway extending from clinical or mammographic suspicion of disease to the completion of all adjuvant therapies and follow-up."²⁵ Generally, the clinical care pathway is divided into a series of care intervals that identify diagnostic and treatment procedures and typically includes:

- Dedication-referral (first clinical or mammography evidence)
- Biopsy (first pathological confirmation)
- Surgery (first definitive surgery)
- Referral to a cancer care agency (referral received for adjuvant therapy)
- Patient contact (by cancer care agency)
- Radiology/oncology consultation (first consultation appointment)
- First adjuvant therapy (initiation of treatment)²⁶
- Rehabilitation/follow-up services (if necessary with primary physician or specialist/auxiliary health care providers).

Though the care pathway appears linear, in Saskatchewan (particularly rural and northern Saskatchewan), moving along the pathway from diagnosis to treatment is a complicated process that occurs, "over multiple visits, often in different locations" and involves, "a variety of health care providers and specialists"²⁷ and other non-medical personnel. Each care interval requires a coordination of health services from several programs provided by either the SCA or health region, or both. The process involves a number of time sensitive treatment therapies and is a time consuming process as the service must not only be ready and available, but the individual patient must also be medically ready to receive the treatment. For the individual, moving between the care intervals is often marked by periods of waiting for the next care interval to begin.

It is beyond the scope of this review to examine the clinical care pathway in its totality. However, the treatment of "early stage breast cancer is relatively standardized for the vast majority of patients for whom surgery is potentially curative and adjuvant therapies are commonly recommended."²⁸ This review, therefore, will be limited to the SCA and its provision of adjuvant chemotherapy following surgery for women diagnosed with early stage breast cancer. In the review we focus on the following intervals between the following events:

- Referral to a cancer care agency (referral receipt for consideration of adjuvant therapy)
- Patient contact (by cancer care agency)
- Oncology consultation (first consultation)
- First adjuvant therapy (initiation).²⁹

Section 3

Waiting, Guidelines, and Benchmarks

3.0 Waiting for Care

It is generally accepted in the care and management of breast cancer that the "earlier a cancer is detected and treated the better the chance the cancer can be eradicated and not recur."³⁰ Being diagnosed with breast cancer is a life-altering experience, and timely access to treatment increases a woman's chance of survival.

Waiting for treatment can be stressful and anxiety-provoking, but waiting for care does not necessarily mean that the wait is medically unacceptable.³¹ There are a variety of reasons why a waiting period may be required and sometimes it may be clinically necessary if the patient is not medically ready to receive the treatment. Throughout the clinical care pathway, the wait times between the care intervals and the care itself are often supported by what are considered to be "best practice" guidelines.

3.1 Clinical Practice Guidelines

Breast cancer care in Canada is supported by clinical practice guidelines. Canadian guidelines for the treatment

and management of breast cancer were developed in the early 1990's when it was noted that there was considerable variation in the ways breast cancer patients were treated across jurisdictions. The guidelines are found in the *Clinical Practice Guidelines for the Care and Treatment of Breast Cancer: A Canadian Consensus Document*. The guidelines were prepared by subject experts and reflect the "best available scientific evidence and extensive consultation with experts in the field."³² The guidelines are reviewed every two years to ensure updated information is added. The guidelines are publicly available in two formats; one for patients and another for physicians. The guidelines are "intended to facilitate discussion between the patient and the physician that may precede a clinical decision."³³

For breast cancer care, the purpose of the clinical practice guidelines is to provide and promote an evidence-based summary of best practices. The guidelines are intended to ensure consistency of care and while there may be variation in care among patients, the guidelines provide a "better definition of the limits within which treatment decisions normally vary."³⁴

A number of the clinical guidelines discuss the optimal time period in which a procedure should be provided to the majority of patients. These time periods have also been referred to as benchmarks.

3.2 Benchmarks

Benchmarks identify a maximum time period, measured in days, weeks, or months, within which the majority of patients should receive treatment.³⁵ A benchmark is typically identified “when scientific evidence shows that the outcome of an intervention is negatively affected after a certain period of waiting has elapsed.”³⁶

Not all breast cancer care guidelines have articulated benchmarks as there is not always adequate scientific evidence to support their establishment. For example, there is a national benchmark for curative radiotherapy, but not for surgery or adjuvant chemotherapy. The current stated national

benchmarks for breast cancer care are set out in Figure 2.

The absence of a benchmark does not mean that if treatment is not provided in a timely manner an individual’s treatment outcome will be negatively affected; nor does timely treatment mean a guaranteed positive outcome. Similarly, the existence of a benchmark for a particular form of therapy does not necessarily mean that if a patient does not receive that particular form of therapy within the specified time period her treatment outcome will be negatively impacted. Rather, for an individual patient, a benchmark provides information on the parameters under which treatment will be provided.

Figure 1: Current Recommended Benchmarks for Breast Cancer Treatment in Canada

Care Procedure	Benchmark
Abnormal screen to diagnosis (biopsy)	• 5 weeks for breast imagery resolution if no tissue biopsy is required • 7 weeks from screen to diagnosis if a biopsy is required (Canadian Breast Cancer Screening Initiative)³⁷
Surgery	• No Canadian benchmark • Some provinces have established targets ranging from immediately (most urgent cases) to several weeks (least urgent). Urgency depends on stage of cancer at time of diagnosis
Radiation	• 4 weeks of being ready to treat for routine cases: 2 weeks for consult wait and 2 weeks for treatment (Canadian Association of Radiation Oncology)³⁸
Chemotherapy	• No Canadian benchmark • Generally accepted practice guideline would recommend that in those cases where surgery has been the primary treatment, adjuvant chemotherapy, if required, should be initiated as soon as the surgical incision has healed – typically within 8 weeks (CBCI Clinical Guidelines)³⁹

Benchmarks also enable the general public to judge the effectiveness of their provincial health care system in providing services as compared to other jurisdictions. In 2004, in response to growing public concerns about wait times in health care, the federal and provincial and territorial governments established ten evidence-based benchmarks

in five priority areas, including cancer radiation treatment.⁴⁰ The respective levels of government agreed to focus on reducing those wait times that were longer than medically acceptable and to achieve meaningful reductions in the five priority areas.

Figure 2: Current Targets and Reported Performance in Saskatchewan for Breast Cancer Treatment

Care Procedure	Provincial Target	Reported Time (Source/Timeframe)
Abnormal screen to diagnosis (biopsy)	No published target.	Breast Biopsy - 80% completed within 3 weeks, 97% completed within 4 to 6 weeks, 100 % of cases completed within 6 weeks (Saskatchewan Surgical Care Network website,⁴³ reporting period October 2009 to March 2010).
Diagnosis to surgery (procedure performed)	- Proven or suspected invasive cancer - target timeframe: 95% are completed within 3 weeks (SSCN website, reporting period October 2009 to March 2010). - Procedures for slow growth or indolent cancer: 90% are completed within 3 months.	Mastectomy (radical/partial combined): 80% completed within 3 weeks, 97% completed within 4 to 6 weeks, 100% completed within 7 weeks to 3 months (SSCN website, reporting period October 2009 to March 2010).
Radiotherapy (RT)	4 weeks ready to treat for routine cases (Canadian benchmark).	92% of ready to treat⁴⁴ cases received RT within the 4 week benchmark (SCA website October 2009 to December 2009).
Chemotherapy	No published target but reported to informally consider the maximum wait time for early stage breast cancer to begin adjuvant chemotherapy as 12 weeks from the date of surgery.	No publicly reported information.

3.3 Meeting the Targets

Benchmarks are based on scientific evidence and therefore do not typically vary among provinces and territories.⁴¹ However, each jurisdiction can set its own targets based on the jurisdiction's capacity to achieve the benchmark. As such, targets are discretionary and considered to be performance goals used to measure a system's "efficiency, communication, capacity and resource utilization."⁴²

Jurisdictional targets are communicated in a variety of ways and can include, for example, reporting on the actual number of cases seen, a percentage of cases seen, or the mean average number of cases seen within the specified time period.

Like other jurisdictions, Saskatchewan has established targets for certain diagnostic and treatment procedures in the care and management of breast cancer. Surgical services for breast cancer patients are provided by the health regions, while radiation and systemic treatments are provided by the SCA. They separately report on their performance in meeting both national benchmarks and provincial targets. While we have combined these results in Figure 3, this information is not readily available. Individual patients in search of wait time information must actively seek it from both organizations.

The SCA reports on radiation and medical oncology services for all cancer patients, but does not specifically report on adjuvant chemotherapy for breast cancer patients. However, the SCA advised the Ombudsman investigators that it has informally accepted the adjuvant chemotherapy benchmark established by a clinical study conducted in the province of British Columbia.⁴⁵

The British Columbia study was a retrospective review of 2,594 patients diagnosed with Stage I and II breast cancer who received adjuvant chemotherapy between 1989 and 1998 at the BC Cancer Agency. The study suggested that that initiation of chemotherapy up to 12 weeks after surgery provided, "equivalent protection from recurrence and allowed women sufficient time to gather information, consider their options and be actively involved in treatment decision-making, the latter of which has shown to reduce anxiety and depression associated with breast cancer."⁴⁶

Although the SCA reported using the 12 week interval as an informal benchmark, it has not been formally adopted and a provincial target has not been developed to gauge the SCA's performance in meeting the benchmark.

3.4 The System's Impact on Wait Times, Benchmarks, and Ability to Meet the Targets

Though the SCA has not formally adopted the 12 week benchmark, the time between a woman's surgery and consultation with an oncologist and initiation of adjuvant chemotherapy has been regarded as an "indicator of quality of cancer care that is used as a measure of system efficiency, communication, capacity and resource utilization in other jurisdictions."⁴⁷ As reported by Rayson *et al.* (2007), a number of provinces use this interval as a major or

sole measure of cancer care wait times and report this on their public websites.⁴⁸

Wait times are influenced not only by patient-centred factors, but also environmental and system factors. These factors can include, but are not restricted to, the availability of oncologists and nursing staff, the availability of equipment, the capacity of the SCA to provide services, and more generally, the financial resources provided to the SCA to fulfill its overall mandate.

Two system factors that are often not considered on their own as impacting wait times are the administrative structures in place to support the wait lists and the processes used to manage them. Generally, multiple layers of administration or systems can negatively impact the final goal of a wait list – specifically, timely and equitable access to health care services.⁴⁹ The actual administrative policies and accompanying processes used by the system to refer and then schedule patients for services can also affect how long someone waits for treatment. Ineffective referral and scheduling processes that are paper driven, have limited technical support, or use multiple databases do not support either timely or equitable access to care.

How individuals are “managed” while on the wait list can also influence their perceptions as to whether or not they are receiving timely care. Studies have demonstrated that the interval between surgery and initiation of adjuvant chemotherapy is a period of time that can cause anxiety and feelings of loss of control. How an individual patient is treated and what support and information are provided can either assist with or add to the already heavy burden she is facing.

In order for the individual patient, service providers, and the general community to

have confidence in the system, managing a wait list requires transparent and efficient administrative procedures and processes. It also requires effective case management policies and practices to ensure that individual patients are treated in a fair and equitable manner and that any decisions made in relation to a patient can be supported.

Section 4

The Saskatchewan Cancer Agency and Its Waiting Process

4.0 The Saskatchewan Cancer Agency (SCA)

The SCA operates two cancer centres, the Allan Blair Cancer Centre (ABCC) and the Saskatoon Cancer Centre (SCC). In addition to the centres, the SCA in partnership with regional health authorities, oversees 16 community treatment programs providing cancer treatment throughout Saskatchewan through a program called the Community Oncology Program of Saskatchewan (COPS). In addition to oncology services, COPS provides additional medical and social support services. The SCA is also in charge of other initiatives and programs.⁵⁰

All medical and radiation oncologists in Saskatchewan are employed by the SCA and work out of either the ABCC or the SCC. The cancer centres, though under the SCA, are managed as separate entities and each centre independently accepts its own patient referrals, prioritizes its own patients, and manages its own wait list for cancer treatments and services. Each centre does so through its own referral centre or office.

At the time of writing this report, the ABCC and the SCC each maintained separate wait lists.⁵¹ The SCA has since advised that it has one provincial wait list and is considering

moving to a single point of referral. Though the SCA may have one provincial list, it still operates two separate referral points and as a result, two wait lists exist.⁵² In describing the wait list process, this report will refer to the two separate entities as the cancer centres, indicating that both use a similar process unless otherwise indicated.

The wait lists at each cancer centre include all patients referred to that centre with all types of cancer who are waiting for the scheduling of their first appointment with an oncologist.⁵³ The variety of patients, cancer types and sites, and treatment needs on each wait list at any given time can add complexity to managing the wait lists.

4.1 The Process from a Patient's Perspective

When a woman is diagnosed with breast cancer, even though the treatment itself may be complicated, the process to access treatment should be fairly straightforward. From a patient's perspective, once diagnosed with breast cancer and in need of treatment, she is referred to a treatment program. The process for waiting to see a doctor to receive treatment does not seem to be a complicated one.

However, when examined from the perspective of the treatment agency - in this case the SCA - the process from referral to first appointment with an oncologist is significantly more complicated, as is shown in Appendix A.

4.2 The SCA Process

4.2.1 From Definitive Diagnosis to Referral to the SCA

Once a woman has been given a definitive diagnosis of breast cancer, the first and primary form of treatment is often surgery. In order to become a patient of the SCA, a woman⁵⁴ must be referred by a doctor in the community.⁵⁵ This is usually her surgeon, although her family doctor or another doctor can also make a referral. The ABCC and SCC will not accept self-referrals directly from patients. A referral to the ABCC or the SCC can occur prior to surgery or following surgery.

4.2.2 From Referral to First Contact

Community Doctor:

also referred to as a "doctor in the community", this refers to any doctor working outside of the SCA and includes family doctors, surgeons, and other specialists.

Women are typically referred to the cancer centre closest to their home community. However, a woman can be referred to either centre based on her individual situation and preference.⁵⁶

Once referred, all patients receive an informational package⁵⁷ containing general information about available treatments, what a patient might expect when going through treatment, side-effects of treatment, and information about the staff, resources, and physical space at her particular cancer centre.

System Navigator:

a person, typically working in or with the health care system, who assists patients and their families by guiding them through the journey, providing information, being a consistent contact, and otherwise providing necessary support and guidance.

The Patient Access Coordinator

In addition to the informational package, within five days of referral all new patients are contacted by the cancer centre's Patient Access Coordinator (PAC).⁵⁸ The PAC advises women that their referral has been received and they have been entered as patients of the SCA. All new patients are given the PAC's contact information in case they have any questions or concerns. This provides the individual woman with a direct contact at the SCA until she is able to see an oncologist. To some extent, the PAC acts as a quasi-system navigator providing a single point of contact and responding to a patient's general questions or concerns. If the patient has questions about her medical care, has other clinical questions or is symptomatic, the PAC refers the concern to the referral centre nurse, who can provide information and answers for the patient's questions.

The PAC is directly involved in the patient's case only up to the patient's first appointment with her oncologist. Once

a woman is assigned an oncologist, a care team is designated to assist her throughout her treatment process at her specific centre. The care team includes the oncologist, a nurse, a social worker, and a pharmacist. However, since the care team is not designated until the first appointment with an oncologist is scheduled, from the point of referral until first appointment with an oncologist the woman is without individualized support beyond the general support provided by the PAC.

Patient Orientation Sessions

The PAC is responsible for the Patient Orientation Sessions that are held at each of the cancer centres. These are group sessions, typically held every two weeks, for each patient and her support person or persons (such as a spouse, other family member, a close friend). The orientation sessions are open to all new patients of the SCA, regardless of the type, nature, or site of their cancer. The Patient Orientation Sessions provide general and specific information about the SCA, the cancer centres, available resources, and the

treatment pathway. In terms of the treatment pathway, the PAC provides information about the course of treatment, what to expect during treatment, and what will be expected of the individual patient by her designated care team.

At these sessions psychosocial support is addressed and

patients are provided with information and "tips" about how to emotionally cope with the cancer diagnosis and resulting treatment. Information is also provided about other non-medical resources available at the cancer centre, including the patient lodge, dietician services, psychosocial services, and the "Look Good Feel Better" program.

4.2.3 Obtaining a First Appointment or First Consultation with an Oncologist

Following the first contact by the cancer centre, a patient typically will not be contacted again until her first appointment with an oncologist has been scheduled.⁵⁹ The length of time a woman will wait to see an oncologist depends on a number of patient-centred factors including the type, site, and grade of the cancer, whether the cancer has spread beyond the initial site, and other clinical concerns. Patients will not be seen by an oncologist until they are medically ready to be seen. Organizational factors, such as the availability of oncologists, will also affect how long a patient will wait.

While the woman is waiting for an appointment, a number of tasks occur internally at the cancer centre that move the woman forward on a wait list from referral to first appointment. Managing and supporting the wait list is an administrative process that organizes the delivery of needed medical services to a targeted population. The process mainly involves two types of decisions: clinical decisions and administrative decisions. This review focuses on administrative decisions and tasks.

When the cancer centre receives a referral, the first administrative task is to determine

Chart:

the formal physical/paper file at the Cancer Agency containing information such as the patient's diagnosis, health information, test results, and, once agreed upon by the patient and physician, information about the treatment.

"The wait list is a live and active document that clinical staff utilize to prioritize patient appointments."⁶³

if the patient has previously been a patient at either centre.⁶⁰ For new patients, a patient file or chart must be created.

The process of creating a chart and entering the woman as a patient of the SCA involves a number of steps completed by administrative support staff. These steps do not involve clinical decisions or require specific clinical knowledge or expertise.⁶¹ This process determines what type of appointment a patient will require - either a new patient appointment or review appointment.

If the individual has never been a patient of the SCA or if she was previously treated at the SCA but has now been diagnosed with a new cancer occurring at a new site, the patient will be placed on a wait list for a "new patient standard appointment." If the cancer has recurred in the same site, it is then determined if the patient had been seen by a doctor at the cancer centre within the last year. If the patient had not been seen within the last year and was discharged by the cancer centre, then she will also be placed on the wait list for a new patient standard appointment. If she had been discharged and her previous physician is no longer with the SCA, then she will be placed on the wait list for a "new patient - new to provider appointment". Ongoing patients who request a second opinion, a different oncologist, or whose oncologist has left the cancer centre, will also be booked for a new patient - new to provider appointment.

While the SCA tracks the patients differently for its own records, all new patient appointments, whether standard or new to provider, are booked for the same amount of time.⁶² In addition, all patients

waiting for new patient appointments to be scheduled are placed on the wait list. This is in contrast to patients who were previously patients of the SCA and who have cancer in the same site as before. Whether or not those patients were discharged, if their previous physicians are still working at the SCA, they are booked into a "review appointment" with the same physician and they do not have to go onto the wait list.

This process can be seen in Figure 4.

Once the chart moves from initial referral and the patient is placed on the new patient wait list, the chart is then passed over to clinical staff for triaging. Of course, from the patient's perspective, she has already been waiting for treatment prior to being placed on the wait list at the SCA.

While the diagrams do not clearly indicate this, the process while patients are on the wait list is fluid and continuous and involves the patients' charts being reviewed and monitored regularly, often several times each week. This means that the charts are frequently triaged several times while the patient is on the wait list in addition to the first triage performed by the nurse and oncologist.

Triage is a clinical term that for the purposes of this review indicates that a clinical professional is reviewing a patient's chart in order to sort it and determine what type of treatment the patient requires and how quickly the patient requires that treatment. There are two different types of triaging that occur, each completed by separate clinical staff for different purposes. For our purposes we will refer to these as initial triaging and medical triaging. Often, both initial and medical triaging of a chart occur simultaneously, or are completed closely together.

4.2.4 Initial Triage of Patient Files

The initial triage is completed by a registered nurse from the referral centre (referred to here as the nurse or the referral centre nurse).⁶⁴ The purpose of the initial triage is to sort the charts by the type of treatment that the patient requires and the urgency of the matter. The initial triage is based on the information provided by the referring doctor, but may also involve clinical decisions or assessments made by the nurse.⁶⁵

Although it will be explored in more detail below, at the time of our review there were separate processes used for medically triaging charts based on the type of treatment required and which cancer centre was doing the triaging. Therefore, the initial triaging by the nurse will have an impact on who will medically triage the chart based on the type of treatment the patient requires.⁶⁶

The nurse also triages the charts based on urgency of care and places the chart in one of three categories: emergent, urgent, or standard. Emergent and urgent cases will generally be seen much more quickly than standard cases and in fact, will often be seen on the same day or the same week that the referral is received by the cancer centre. Urgency of care is typically based on the information provided by the referring surgeon or family doctor, but may also involve a clinical assessment by the nurse. The nurse will often confirm the urgency of cases with an oncologist. The nurse will also check with an oncologist any cases that are unusual or about which they are unsure.

The nurse enters the patient into the referral centre's main computer program, CMS, and marks the chart in what that program calls its "billing" function. Being unrelated to billing, new patients are flagged though this

function, which does two things: the names are used to create lists used when volunteers mail packages to all new patients; and it also informs the PAC about all new patients.

The nurse updates the printed wait list by manually writing the patient's details in the steno notebook. The nurse also updates the comments section of the computer wait list with any relevant information, including if the centre is waiting on anything prior to setting an appointment for the patient (such as waiting for the patient to heal from surgery, waiting for further tests or information, or waiting for the patient to be ready to see). The nurse ensures that the patient's physical chart goes for medical triage to the appropriate oncologist. Many of the duties performed by staff in the initial triage involve clinical assessments. However, within the clinical assessment there are some administrative actions performed by the same clinical staff (such as data entry), which are arguably separate from the clinical duties.

4.2.5 Medical Triage

The appropriate oncologist will also triage the chart, separately from the nurse. In the medical triage, the oncologist reviews the chart for any important information, to order any outstanding images or lab work that an oncologist will need at the patient's first appointment, and to create a prioritization list of patient charts. This process is described in Figure 5.

The medical triage involves clinical assessments and decisions. The prioritization that the oncologist performs will be used by the nurse when booking first appointments with oncologists as they book the patients with the highest priority first. This prioritization is not the same as, but is related to, the urgency of a chart. During the prioritization, the oncologist may find

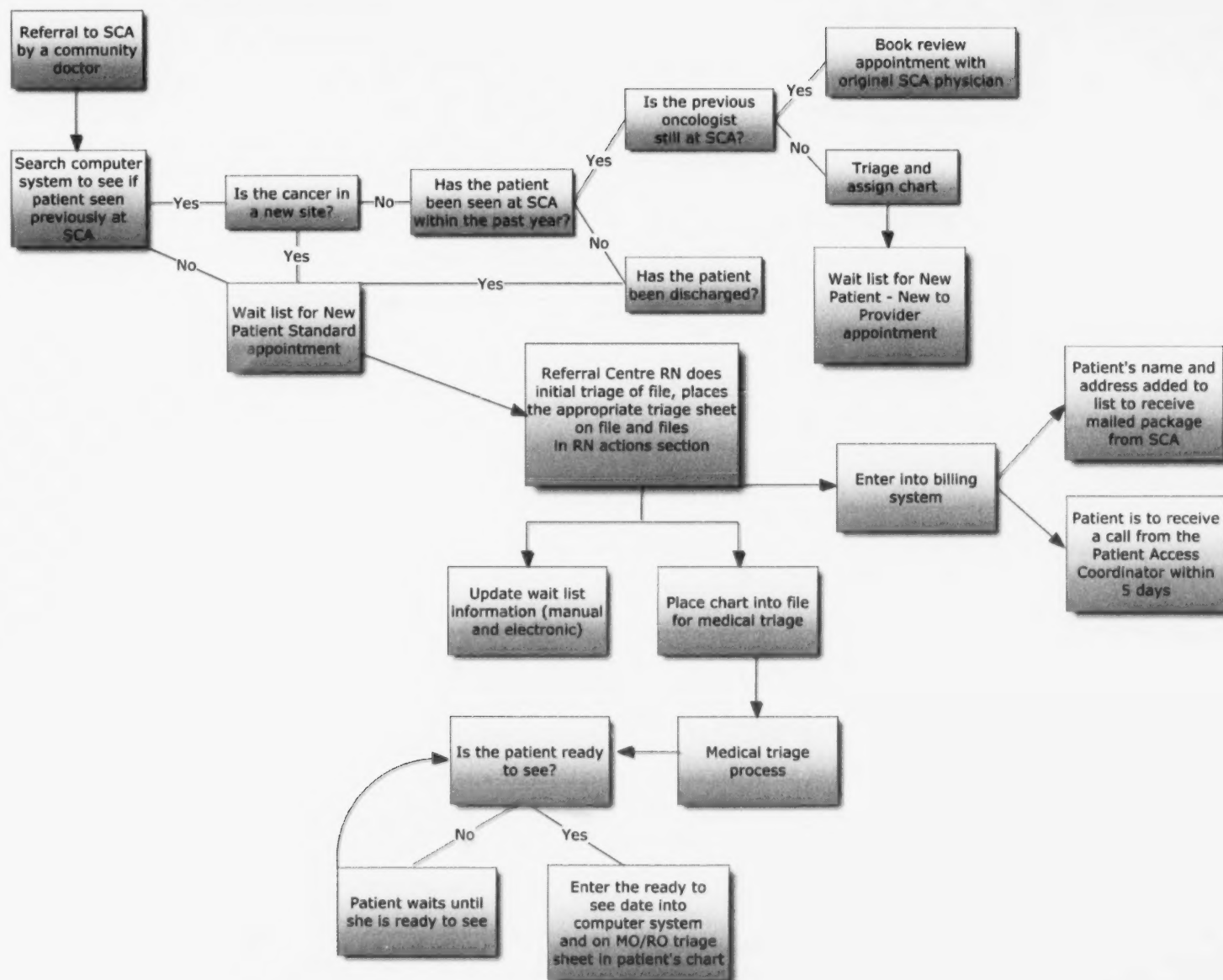
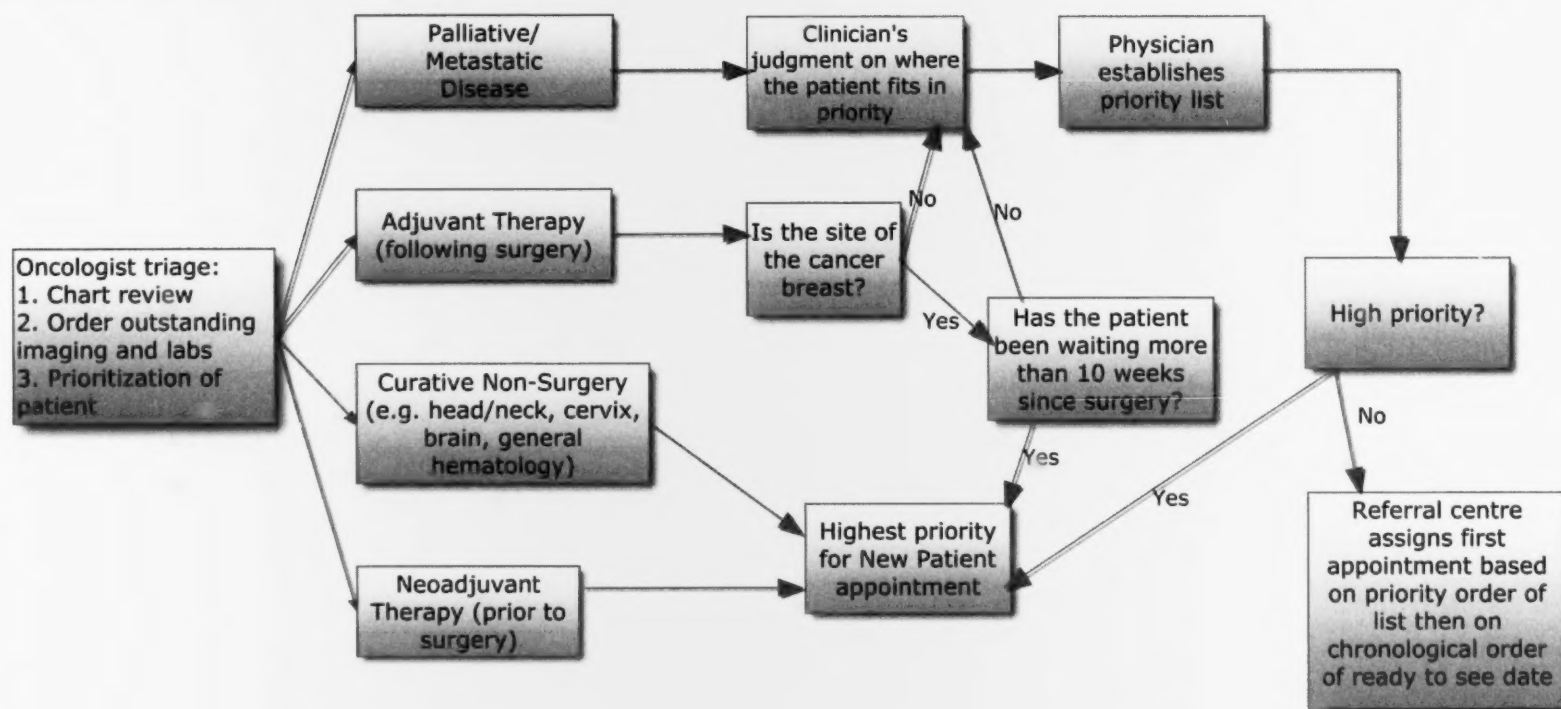
Figure 3: Entry into Patient Status

Figure 4: Medical Triage Process



cases that were not referred to the cancer centre as emergent or urgent, but that require very prompt treatment. These charts will receive a high priority for treatment so that they are considered akin to emergent and urgent referrals.

When prioritizing a chart, the oncologist attempts to determine the type of treatment a patient needs and then place the case into one of four categories: neoadjuvant therapy, curative non-surgery, adjuvant therapy, or palliative or metastatic disease.⁶⁷ The highest priorities for an appointment with an oncologist are those patients requiring neoadjuvant therapy and curative non-surgical therapies. Also of a high priority are patients requiring adjuvant therapy for breast cancer that have already been waiting longer than ten weeks since surgery.

As stated earlier, there are different processes for medical triaging at each of the provincial cancer centres. At the ABCC, the Head of Medical Oncology reviews and triages all charts that are waiting for a first appointment with a medical oncologist. Only when the patients' charts have been assigned a first appointment are the patients connected to an oncologist and an accompanying care team.

At the time of this review, the process used for triaging medical oncology files at the SCC was different.⁶⁸ During the initial triage process, the nurse assigns all charts to a particular oncologist who will provide oncology services to the patient.⁶⁹ The oncologists then triage all of their own charts.⁷⁰

4.2.6 Determining Eligibility for the Next Available Appointment

As described in Section 3.3, for patients with early stage breast cancer there is an

informal benchmark of attempting to begin adjuvant chemotherapy within twelve weeks of surgery.⁷¹ This is why breast cancer patients who have waited longer than ten weeks since surgery are considered a high priority for a new patient appointment. For breast cancer patients who have not been waiting for longer than ten weeks since surgery, it is up to the oncologist triaging the file to determine where the patient fits in the priority of the wait list.

Based on the priority of the wait list established by the oncologists triaging the charts, the nurse assigns the next available appointments. If there are two charts with an equal priority ranking, the nurse assigns the next available appointments based on which patient was first medically ready to be seen.

While a chart is on the wait list, it will be reviewed several times by both the nurse and oncologist. This means that when circumstances change, the patient's priority ranking should change as well. For example, if new symptoms appear that indicate chemotherapy is required sooner than previously thought, the file will be reviewed and very likely, the priority of the file will change. As the case remains on the wait list, it is continually monitored to ensure women are seen within the twelve week benchmark whenever possible. The closer a woman is to waiting for longer than ten weeks from her surgery, the higher a priority she becomes to be scheduled for a first appointment with an oncologist and begin treatment.

Another duty of the nurse is to assess whether the patient is medically ready to be seen. This involves both clinical aspects, such as whether the patient has sufficiently healed after surgery or is able to physically withstand treatment, and other aspects, such as whether the patient has plans to

leave the province. If the patient is ready to be seen, the nurse enters the "ready to see" (RTS) date into the centre's computer system. If the patient is not ready to be seen, then the case is on hold until the patient is ready to be seen. The nurse notes in the comments section of the wait list information the reasons why the patient is not ready to be seen, and the case is continually monitored.

The assessment made by the nurse of whether the patient is ready to be seen involves a clinical assessment completed by the nurse. This involves interpreting clinical information provided by other clinicians, especially the referring doctor and oncologist involved in triaging the file.

4.2.7 Scheduling First Appointments with an Oncologist

Apart from the initial triage process and the assessment of whether a patient is ready to be seen, many of the remaining tasks undertaken by the nurse are administrative tasks not involving or requiring clinical knowledge or expertise.

The process for scheduling first appointments is shown in Figure 6.

The nurse generates reports in two of the computer systems that the referral centre uses for scheduling - a "New Patient Slot Report" and a "Wait list Custom Report." The "New Patient Slot Report" lists all of the oncologists and their available appointment slots for each upcoming week. The "Wait list Custom Report" is the tool from which appointments are booked. Although the reports are generated by a computerized program, much of the work in managing the lists between report runs is completed manually.

Using these reports, the nurse assigns patients who are ready to be seen and who are in order of priority next on the wait list to any available new patient appointment slots. The nurse manually writes the appointment time in the patient's chart and on the two generated reports.

Part of the nurse's task is determining if the centre has the capacity to meet the immediate need. According to the Agency's procedures if there are more patients with the highest priority requiring appointments than there are available appointment slots, the nurse is to then check the availability of service at the other SCA cancer centre. The actual practice at the time of this review and currently is that the Operations Committee of the SCA⁷² monitors the provincial wait times and the wait lists of each centre and if the waits are uneven, the Operations Committee instructs the referral centre nurses to begin offering patients the option to go to the centre with the shortest wait time. If the other cancer centre does not have the service capacity required to meet the needs of the patients, an out-of-province referral option should be given to both the patient and the referring physician. If there is capacity at the other cancer centre, then the patient should be asked if she would consider being seen at the other site, if she was not already asked this question.⁷³

If the patient agrees to be seen at the other site, then the patient's chart is physically sent to the other cancer centre and the referral centre nurse at the other centre assigns a first appointment based on the priority order of that centre's wait list and then based on the chronological order of the ready to be seen date. This means that the patient is transferred to another wait list. If the patient does not agree to be seen at the other site, then the patient will remain on the wait list at the original centre until an appointment is available.⁷⁴

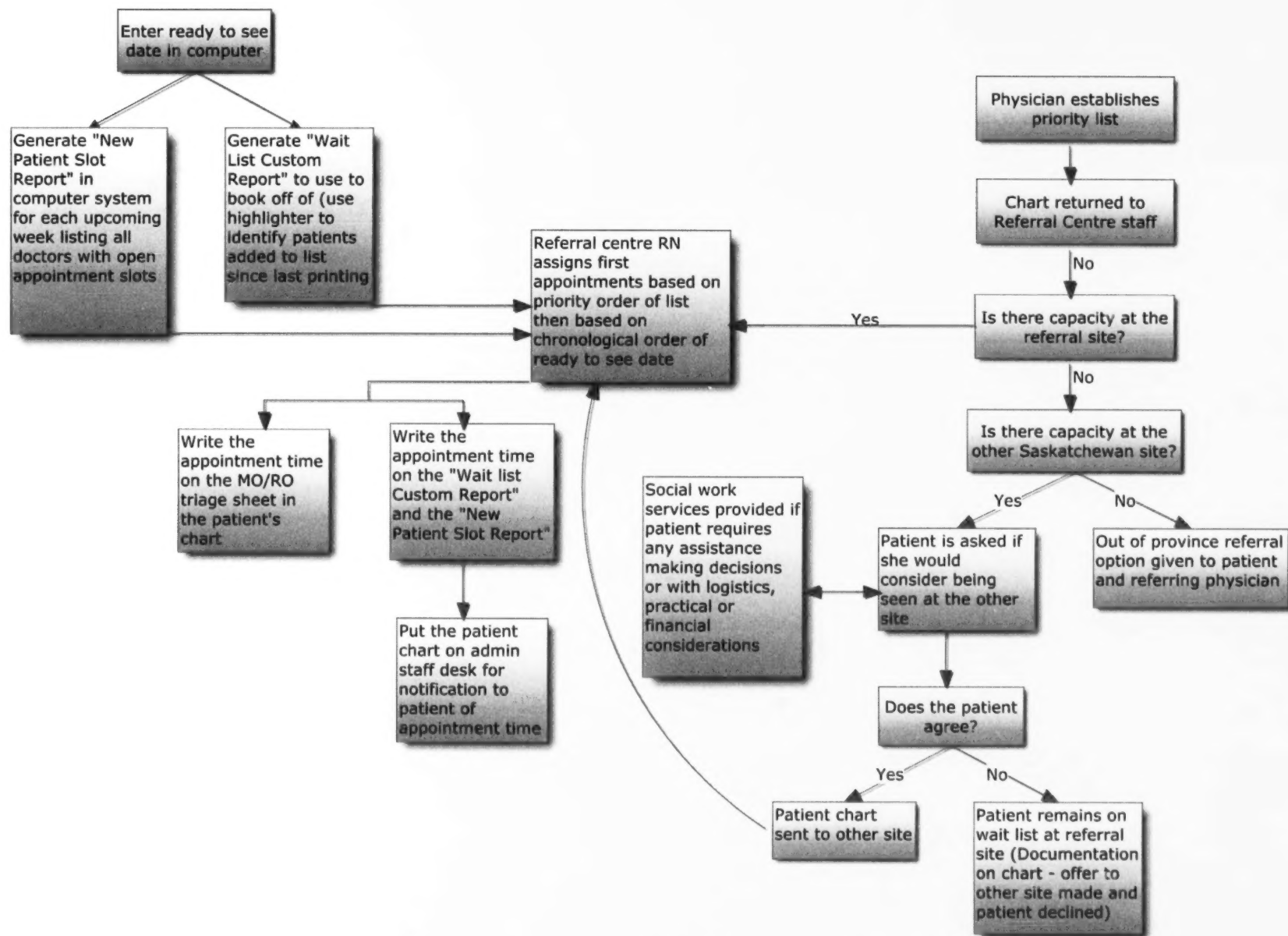
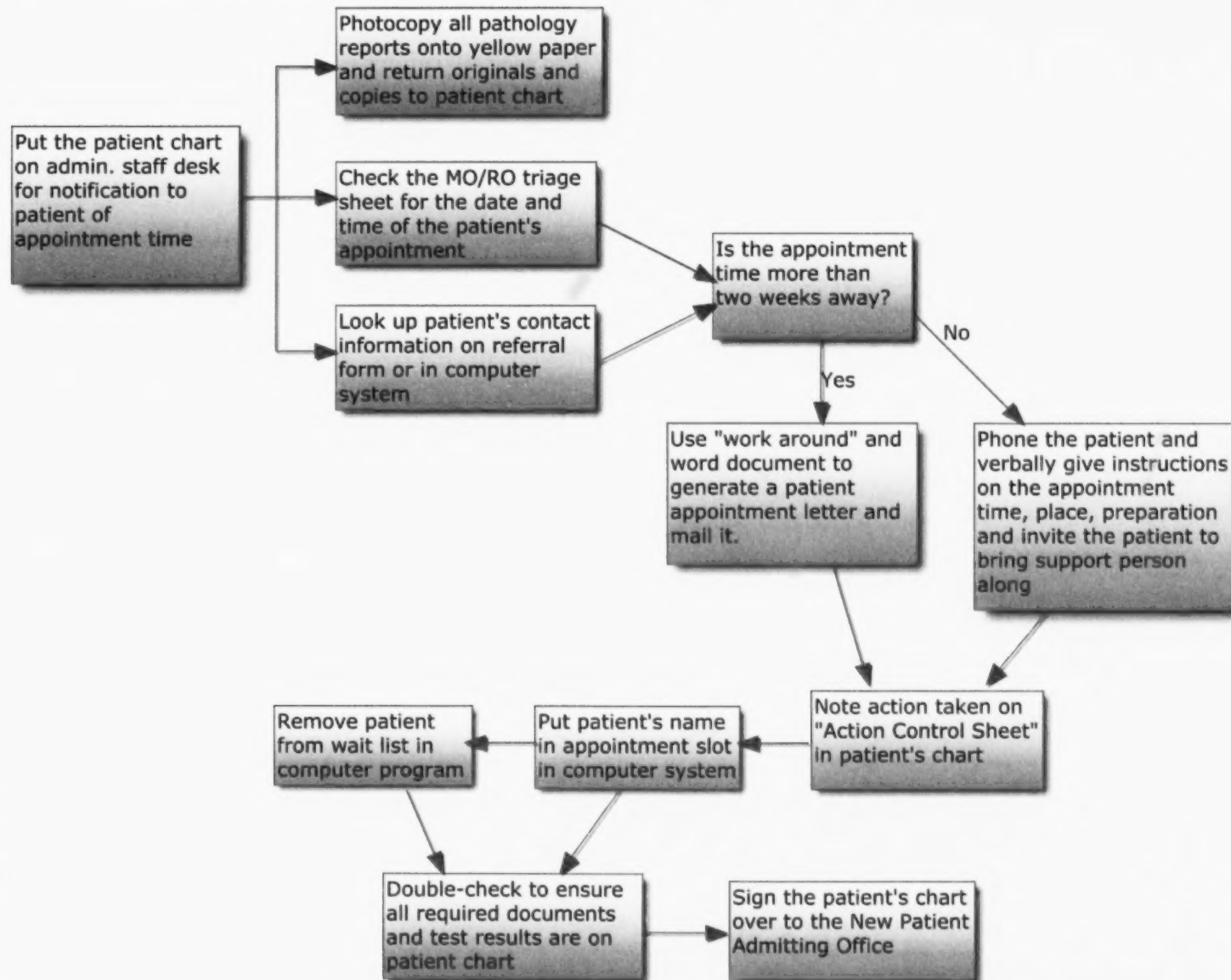
Figure 5: Assigning First Appointments

Figure 6: Exiting the Wait list



4.2.8 Exiting the Wait List

Once a first appointment with an oncologist has been scheduled, the nurse provides the chart to an administrative staff person. The administrative staff person ensures that the patient's chart is complete and notifies the patient about her appointment. This process can be seen in Figure 7.

If the appointment is more than two weeks away from the date on which the administrative staff person is notifying the patient, then the administrative staff person produces a patient appointment letter which advises the patient of the date, time, and location of her appointment. If the appointment is less than two weeks away, then the administrative staff person contacts the patient by telephone to verbally give instructions on the appointment time and what the patient should do in preparation for the appointment, and invites the patient to bring a family member or friend with her to the appointment. After notifying the patient, the action taken is noted in the patient's chart.

Finally, the administrative staff person then removes the patient's name from the centre's computerized wait list and signs the patient's chart over to the New Patient Admitting Office.⁷⁵ The patient has now officially exited the wait list even though she is still waiting for the first appointment with an oncologist.

4.3 Information Provided to a Patient While She Waits

As stated above, unless the patient initiates it, there is typically no contact made by anyone from the SCA or the cancer centre following receipt of the mailed package and the initial telephone contact of the PAC up until the patient is notified about her first appointment with an oncologist.

Historically, patients were not told there was a wait list or that they were on it. In the last two years, the SCA has begun to advise patients about the wait list. Now, in information mailed to the patient and in the initial PAC telephone contact, patients are advised that there is a wait list; that they are on the wait list; how many people are on the wait list; and, on average, how many new people are added to the wait list each month. At the time of our review, patients were not provided information on where they fell on the wait list or how long, approximately, they might expect to wait.⁷⁶

It is not clear that patients understand how the wait lists work, including the fact that they will not move on the wait list until they are ready to be seen. Patients are not considered ready to be seen until all necessary tests have been performed, a proper diagnosis is obtained, any necessary surgery for adjuvant patients has been done, and the patient has sufficiently healed from the surgery, among other considerations.

Waiting to see any doctor, and especially a cancer doctor, is often difficult and can cause significant anxiety for the patient. An individual's perception of how long she has had to wait may be affected by when she was referred to the SCA. A woman who

is referred prior to receiving surgery may feel as though she has been on the wait list longer than another woman who was referred following her surgery. Though the first woman is on the list, her name is held and she is not eligible to see a doctor until she is medically ready to be seen which is not until after she has had her surgery. A woman referred prior to surgery and a woman referred following surgery will see an oncologist when medically ready – and both women may be seen within the same time period following their surgeries, especially if the grade and nature of their cancers are similar. However, the woman who is referred prior to her surgery will undoubtedly feel she has waited longer.

The Ombudsman investigators were told by the SCA that it did not provide time estimates to patients, at the time of our review. The SCA felt that there are too many variables affecting its ability to make proper estimates of when an individual will see an oncologist. SCA staff interviewed for this report stated that they worry that if the estimate is incorrect, it will cause more stress and anxiety for the patient than receiving no estimate.

An individual's perception of how long she has waited and whether that wait is appropriate will be affected by the quality of the information she is provided. The SCA and its cancer centres appear to provide limited information to individual patients about the wait list in general, what it means to be placed on the wait list, and the estimated time frame for the wait.

4.4 Process Summary

It is important to recognize that the experience of patients who are waiting

for an appointment with an oncologist is entirely different from the experience of the staff in the referral centre at each cancer centre. From an individual patient's perspective, the process should be rather straightforward. The process used by the referral centre staff to manage patients through the wait list is intricate and complex. Even the various diagrams of the process do not fully provide a true understanding of the intricacy since many of the steps in the diagrams are actually performed multiple times in various orders in an attempt to try to ensure that every patient of the cancer centre is seen in a timely and appropriate manner. Because the process is the same for and the wait lists include patients with many different types of cancers in various sites in the body requiring various types of treatment, this adds to the difficulty in attempting to manage everyone.

Added to this is the fact that the referral centre staff are required to work within multiple computer programs and a manual system, and have to keep track of all of the patients through these various means to ensure that each patient receives individualized and appropriate help.

Many patients do not understand the complexity of the wait lists as the SCA does not provide adequate information to patients about the lists and its management of the lists as it relates to the patient's individual case. Without information, patients' anxiety may be increased and patients may feel that they are being treated unfairly. Information sharing is an important aspect of a fair process in all service industries, including health care, and for government decision-making more generally.

A Matter of Time:
An Investigation into the
Management of Wait Lists for
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Part 2

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Section 5

Capacity

5.0 Operational Capacity at the SCA

Staff interviewed for this review consistently commented on and linked the concerns raised about the wait list for adjuvant chemotherapy to the Agency's often limited and fluctuating resource base - specifically the shortage of medical oncologists. They reported that at times the demand for services outweighed the Agency's capacity to meet that demand. Though there is no doubt that the Agency's clinical staff are a significant and valuable resource, how the Agency manages and supports this and its other resources has an impact on its ability to effectively manage its wait lists.

The SCA's operational capacity refers to the level of service output the Agency can potentially achieve and maintain over a period of time. As with any service system, it is unlikely that the Agency can operate at full capacity for prolonged periods because a number of external and internal factors will impact its potential output. External factors, such as the availability of medical oncologists, are often beyond the control of the Agency and will obviously impact services. Other internal factors, well within the control of the SCA, can also impact the Agency's capacity to provide services. Moreover, regardless of whether or not it is always able to match capacity and demand, the SCA has an obligation to provide

equitable and timely access to treatment for all patients, both under PFCC principles and in order to be fair.

Managing the Agency's capacity involves managing its limited resources, which include its labour force (both clinical and administrative staff), technology and equipment (medical and otherwise), office and clinical space, and inventory. Capacity management also includes managing the Agency's processes—in this case, the wait list process from point of referral to point of first oncology consultation—as well as foreseeing or dealing with any capacity restraints or impediments in that process. Capacity restraints and impediments in the process can produce bottlenecks and therefore, effective capacity management is critical for the organization to operate efficiently.

Many service agencies fail to recognize and define what is meant by their organizational capacity and some narrowly define their organizational capacity along staff resource lines. In interviews conducted for this review, SCA staff narrowly identified capacity as being restricted to external factors such as shortages of medical oncologists or the lack of a provincial e-health system.⁷⁷ Understanding the true capacity of the Agency and effectively managing that capacity will avoid capacity-demand mismatch.⁷⁸

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5.1 Managing Its Staffing Resources

The majority of SCA staff interviewed for this review reported that the primary reason the Agency was experiencing difficulties in effectively managing its wait lists was simply because it did not have enough qualified medical oncologists to meet the demand for its services.

Historically, when an oncologist left the Agency and was not replaced in a timely manner it created a "crisis", and often a significant expansion of the wait list. Patients who had already been assigned to the oncologist who was leaving or left had to be re-assigned to the remaining oncologists. This created a "bottleneck" on the wait list as all re-assigned cases must be reviewed by the new oncologist and all re-assigned patients must receive a "first appointment" or consult, even if the re-assigned patient is in the middle of her chemotherapy. The bottleneck is created because patients who are on the wait list are not moved onto an oncologist's caseload until the re-assigned patients have all been seen and their therapy continued. This can create a delay for individuals on the wait list, a potential backlog for the Agency, and a significantly higher patient caseload for the remaining oncologists.

According to the SCA, at the time of our review there was a "worldwide shortage of medical oncologists."⁷⁹ Oncology training is not available at the University of Saskatchewan College of Medicine and as a province we must attract and recruit oncologists from other Canadian jurisdictions or internationally.⁸⁰

Ombudsman investigators were told that it is difficult for the Agency to attract and recruit qualified candidates, not only

because those candidates are in high demand world-wide, but because the SCA does not always provide the best or most "creative" incentives for attracting candidates.⁸¹ Those staff interviewed reported that an unusually high workload and the inability to specialize in site-specific cancers also act as a "disincentive" to many potential candidates.

The Ombudsman would agree that the lack of trained oncologists can have an impact on the timeliness of care and contribute to delays in care.⁸² The Agency's requirement that oncologists take on more patients when there is a resource crisis is not sustainable in the long-term. Increasing the work loads of already overloaded physicians is likely to lead to further recruitment and retention issues within the SCA and may actually further decrease its capacity over time.

5.1.1 Maximizing Resources – Getting the Right Person to do the Right Job at the Right Time

Ombudsman Finding

The process used by the SCA to move a case from point of referral to the first consultation/appointment with an oncologist does not always maximize the skill set of Agency clinical staff.

As outlined in Section 4 (see also Appendix A), the process used by the Agency to move a case from referral to the first consultation with an oncologist involves both clinical and administrative staff. Clinical staff play

a significant role in the process and act as gatekeepers for patients and patient care. They have the ability to influence patient care and advance a patient to the next step in the care continuum. As a significant and valued resource within the Agency, their skill sets must be maximized wherever possible. However, the process does not always appear to maximize the skill sets of Agency clinical staff.

Nursing Staff

Referral centre nurses are responsible for several administrative tasks, including data entry of patient information and the creation and generation of electronic and paper reports and listings of patients.⁸³ Though some of these tasks are tied to accessing a clinical service, others are administrative and may be able to be completed by a properly trained administrative support staff person. Doing so could free up the nurses' time to do clinical work for which nurses are required.

Within the process in use at the time of this review, the first appointment with an oncologist takes a significant amount of the oncologist's time. Ombudsman investigators were told that much of this time was used to provide patient education. In the 2007 operational review of the SCA titled, *Improving Access to Cancer Care: Phase One Report*, the author recommended that the SCA move this part of patient education to an earlier point in the process and have it provided by nursing staff.⁸⁴ Though the Ombudsman did not review the process beyond the point of initial consultation, this previous recommendation does have merit.

Although Ombudsman investigators understand some of the information and patient education that will be provided to a patient is dependent upon a clinical examination and cannot be provided prior to the clinical examination, there is some

general education that may be able to be provided at an earlier point. Moving this type of patient education to the front end of the process to be performed by nursing or other staff provides patients with needed information sooner, thereby giving them time to absorb the information prior to their first appointment with an oncologist. Well-informed patients are better able to participate in decision-making about their care and treatment plan. Ombudsman Saskatchewan does understand, however, that different oncologists will have different ways of managing their cases and their individual patient appointments. The Ombudsman is not suggesting that oncologists change their clinical practice, but rather that the SCA, in partnership with its clinical staff, look for ways to maximize its clinical staff time, skill, and expertise.

Recommendation 1

The SCA review the administrative processes involved in managing the wait list from point of referral to the first consultation/appointment with an oncologist to ensure the skill sets of every member of its clinical staff are fully maximized.

5.2 Clinical Benchmarks and Access Targets

Ombudsman Finding

There is an informal guideline used by the SCA for early stage breast cancer patients requiring adjuvant chemotherapy. Under this guideline, patients should begin their therapy within twelve weeks of surgery.

As is stated in Section 3, benchmarks or practice guidelines, particularly those that include timeframes, can be a useful queue management tool. As found in the *Improving Access to Cancer Care* report, within the SCA, "[t]here is a strong sense that practice guidelines and consistent protocols around care will greatly improve access [to care]."⁸⁵ At the time of our review, the SCA did not have a publicized benchmark for adjuvant chemotherapy for woman diagnosed with Stage I or II breast cancer.

Clinical staff at the SCA advised the Ombudsman investigators that it has "informally" accepted the adjuvant chemotherapy benchmark established by a clinical study conducted in the province of British Columbia.⁸⁶

It is important, however, to understand the point of a benchmark. The value of a stated benchmark for the individual patient is that it provides the patient with an understanding of the time frames under which treatment should typically be provided. From a clinical perspective, it is unlikely that a woman's treatment outcome

will be negatively impacted if she does not receive adjuvant chemotherapy within the exact specified time period. For the general public, benchmarks can be used to judge how effective the SCA, and ultimately, the provincial health system is in providing services in comparison to other jurisdictions.

Recommendation 2

The SCA consider formally adopting its informal benchmark for adjuvant chemotherapy for breast cancer patients and develop clinically appropriate access targets.

5.3 Summary

In any PFCC system, all patients should receive timely and equitable care. When asked why the Agency was experiencing delays in timeliness of care, staff most often cited the shortage of medical oncologists. The Ombudsman agrees that the lack of trained oncologists can have an impact on the timeliness of care and contribute to delays in care. We found, however, that the Agency narrowly defined its operational capacity around the availability of staff, without adequately considering if its existing staffing resources were being used as efficiently as possible. Inefficient use of staff and staff time can affect the timeliness of care as much as the shortage of staff.

Capacity management includes managing the wait list process from point of referral to point of first oncology consultation, as well as foreseeing or dealing with any capacity restraints or impediments in that process. Capacity management also requires one to look at the very construct of the process. We found that the process of moving a

patient from point of referral to point of first consultation/appointment with an oncologist was impacted by the structure of the wait list itself. This will be discussed in more detail in Section 6.

Section 6

Managing the Wait List

6.0 The Construct of the Wait List

Access to health care services often requires waiting. Waiting for services may be required because it is part of the overall treatment plan or because of issues related to operational capacity and capacity management. The establishment and management of wait lists for health care services is largely an administrative function in the health care setting. Decisions related to the wait list speak to the organization of and equitable access to services, not whether there is a clinical need for the service. The clinical decision has already been made. With respect to oncology services, a clinical decision relates to the type of oncology treatment a woman may require; the administrative decision is how, when, and where she will access those services.

How, when, and where a woman will access those services depend on patient-centred factors, but they also depend on many larger system and SCA organizational factors that are beyond the patient's control. It is the larger system and Agency factors that we reviewed and found in certain areas are having a negative impact on the Agency's ability to transition and manage a case from point of referral to initiation of oncology treatment. We begin by looking at the construct and subsequent administration of the wait lists and the Agency's oversight of the lists.

6.1 One Provincial Wait List

Ombudsman Finding

Although the SCA contends it has moved to one provincial wait list to access cancer care services in the province, at the time of this review each of the cancer centres still maintains a separate list of patients referred to that centre. Maintaining two referral centres each operating its own wait list under one provincial agency appears administratively inefficient and can create situations where an individual's access to care is influenced more by where the individual was referred than her clinical need.

Ombudsman Finding

The SCA has re-referred patients between the ABCC and the SCC to address resource (medical staff or equipment) shortages that occur from time to time at one or both of its centres. Re-referring patients is, at best, only a short-term and temporary measure that cannot reasonably be supported in the long term and may, in fact, contribute to future inequities in accessing timely service at one or both of the cancer centres.

Prior to our review, the SCA operated two wait lists managed separately through the ABCC and the SCC. Waiting times on each list and between the lists were not monitored from a provincial perspective. During this review, the Agency informed the Ombudsman investigators that it had moved to one provincial list and had begun to monitor the list and waiting times from a provincial perspective.⁸⁷

Though the SCA contends that it has moved to one provincial list, in actuality there is not one provincial list onto which individuals from across Saskatchewan are referred and from which patients are scheduled for cancer treatment. Rather, Ombudsman investigators were told that each of the ABCC and the SCC still maintains a separate list,⁸⁸ and the SCA now monitors overall waits provincially to ensure equity of access between the centres. When patients at one centre have to wait longer to access treatment than patients at the other centre, the SCA will "re-refer" the patient between the centres.

Re-referring is exactly what it sounds like. It is a process that allows one centre to redirect an already referred patient to the second centre for treatment. When re-referred, the patient moves from the wait list at the first centre onto the wait list at the second centre. The SCA has historically used the process of re-referrals to address resource shortages that occur from time to time at one or both of its centres. For example, in early 2009, those patients referred to the SCC who required an appointment with a medical oncologist were receiving appointments more quickly than similar ABCC patients, due to the loss of medical oncologists at the ABCC.⁸⁹ As a result, a number of ABCC patients were re-referred to the SCC for oncology services.

Re-referring patients is one way to equalize access to treatment between the two centres, but it is only a short-term and temporary measure. As well, SCA staff advised Ombudsman investigators that most patients they have spoken to prefer not to travel to the other cancer centre within the province.⁹⁰

Equitable care is a key attribute of PFCC. According to Commissioner Dagnone, equitable care means that, "[p]atients receive the amount of care they need when they need it, regardless of where they live, their age or ethnicity or other factors."⁹¹ The continued existence of two wait lists managed by two referral centres calls into question whether SCA patients are always receiving equitable care throughout the Agency, although patients may be receiving equitable care within the cancer centre to which they were referred.

Two referral centres each operating its own separate wait list under one provincial Agency certainly appears to be administratively inefficient due to the required duplication of work. In addition, it can create situations where an individual's access to care is influenced more by where the individual lives than by her clinical need. Creating one referral point and merging the two separate lists into one provincial wait list would likely make it easier for the SCA to ensure equal access for all Saskatchewan residents based on the care they require, rather than their geographical residence.

The SCA advised the Ombudsman investigators that it would like to move to a system with a truly provincial wait list with one provincial referral centre, but suggested that it has been unable to do so because it lacks a functioning "e-health" system to link the two cancer centres. Without a functioning e-health system, clinical staff (both oncologists and

nurses) at both cancer centres use and rely heavily on an information system that involves paper charts and filing relevant clinical information that cannot be stored electronically on the SCA computerized systems or shared between the two centres. As a result, the SCA continues to run two separate referral centres and each referral centre is responsible to run and monitor its own wait list.

Recommendation 3

The SCA merge its two wait lists to one provincial list that is centrally managed and supported.

6.2 The Structure and Administration of the Wait Lists

Ombudsman Finding

At the time of this review, the structure of the wait lists could be described as a "patchwork" of information collected and stored using multiple formats, and maintained and updated both manually and through computer programs. This patchwork is administratively inefficient, unnecessarily complicated, and does not support timely and equitable access to care.

The wait lists are essentially two separate listings of patients referred to the SCA for a specific medical procedure or intervention.

The "lists" are the means by which the SCA gathers and stores pertinent patient information used to assess the urgency of care and the readiness of patients to receive care. The wait lists are a tool that the SCA uses to manage patient access to its services. In other words, they are the gatekeeper's key to the gate. It is vitally important therefore, that the lists be supported by effective queue management processes, electronic information, and communication technologies.

The SCA's two wait lists are not a single cohesive listing of patients, but are made up of a "patchwork" of information entered and stored on computer systems and on manually generated paper lists. Staff are required to enter patient information, including some of the same information, onto both computer and paper systems and manage the patient information between these systems. This myriad of information systems is inefficient as it adds unnecessary duplication of work and complexity to the process. The more complicated and multi-step the process, the more opportunities arise for errors and consequent delay.

The situation is further complicated by the fact that there are two separate lists maintained and managed entirely separately by the respective centres. Though the waits on both lists are monitored from a provincial perspective, Ombudsman investigators were told that even with provincial monitoring of the overall waits, patients from the two lists are not typically offered the quickest access to an oncologist provincially unless the SCA was in a state of "crisis."⁹² This is not an efficient way to manage the gateway for an essential health care service.

Recommendation 3

The SCA merge its two wait lists to one provincial list that is centrally managed and supported.

6.3 Fragmented Oversight

Ombudsman Finding

Though many SCA staff, both clinical and administrative, are working in and around the wait lists, at the time of this review there appears to be no one individual at the SCA identified by those working for the Agency as being administratively and clinically responsible for overseeing the wait lists.

There are numerous SCA staff working to ensure that all cancer patients receive timely appointments with medical oncologists but there appears to be no one individual at the SCA administratively and clinically responsible for overseeing the wait lists. The Ombudsman investigators were advised by SCA staff that there is no one staff person responsible for maintaining or overseeing the lists, ensuring the lists are current, and ensuring that patients are being seen in a timely manner. This fact is especially concerning for the Ombudsman.

Overall, we found a lack of ownership of the wait lists and both clinical and administrative staff expressed their confusion as to who among them were

“actually responsible” for the wait lists. There appears to be a gap in leadership at the SCA when it comes to managing the wait lists.

Though we found that those staff we interviewed wanted to do a good job and took ownership for their particular role in the process, we found that no one seemed willing to take ownership of the process as a whole. Any accountability taken appeared fragmented and isolated to the individual’s job function and the individual’s perceived level of authority in the Agency.

One of the contributing factors identified by staff interviewed was the organizational culture within the SCA that at times appeared dysfunctional, leaving some staff cynical of any Agency initiative to resolve problems with the wait lists. When asked what the Agency had done to deal with some of the wait list issues, one senior clinical staff person stated, “I go to a lot of meetings and produce a lot of pretty graphs but nothing else.” Others complained that the Agency solutions have been “band-aid” in nature and do not produce long term sustainable change. The majority of staff we spoke to also described a difficult and divisive historical relationship between senior clinical staff and administrative staff as inhibiting progress.

Dr. Brian Postl, the advisor on wait times appointed by the federal government, found, “in provinces where governments and health departments have placed leadership and accountability squarely with respected clinical leaders, progress has been significant and visible.”⁹³ The SCA needs to create an organizational culture or environment where its clinical and administrative senior staff take ownership for the wait lists.

Recommendation 4

The SCA appoint a senior staff member to be responsible for overseeing the entire wait list for the province, which includes ensuring its integrity, that it is maintained efficiently, that new patients are added quickly, and that all patients receive timely appointments.

6.4 Summary

Ombudsman Saskatchewan believes that the SCA is trying to ensure that all patients receive timely and equitable care. However, the structure of the wait lists and the fact that two lists exist, each managed independently without clear oversight, does little to assist the SCA in its goal of providing equitable access to cancer treatment. Rather, two separate lists operating independently can mean that access to treatment is more dependent on where one resides geographically in the province than one's medical needs.

Beyond addressing the structural issues now present, any new system or renewed process requires technological support. At the time of this report, the wait list is supported by computer systems, but much of the process is also paper-driven. In order to move away from the process in place at the time of this report, the SCA will need to examine its information technology in place. Section 7 will examine the issues, as found by the Ombudsman investigators, related to the information technology being used to support the wait list process.

Section 7

Information Infrastructure and Supportive Technology at the SCA

7.0 State at the Time of Our Review

Several SCA staff advised the Ombudsman investigators that the Agency has been unable to resolve a number of the inefficiencies identified with the wait lists primarily because, at the time of this review, the Agency lacked a functioning e-health system that links the two cancer centres.⁹⁴ Without a functioning e-health system, clinical staff (both oncologists and nurses) at both cancer centres use and rely heavily on an information system involving paper charts that file relevant clinical information which cannot be stored electronically on the SCA computerized systems or shared between the two centres. This produces a number of administrative inefficiencies that impact the Agency's ability to manage a case from point of referral to initiation of oncology treatment.

Some individuals in the health care system have suggested that adding information technology will not solve the problem and that technology is often seen as a panacea for the system's problems. The Ombudsman agrees with these two statements. Technology alone will not solve the resource capacity and efficiency issues now facing the SCA. However, the Ombudsmen has found that the information technology used by the Agency at the time of this review poses a significant impediment to change.

The limited technology available to staff at the cancer centres impacts the Agency's ability to effectively and efficiently manage not only the queue for cancer care services, but also the Agency's limited resources and ultimately, the provision of services itself.

7.1 Information Technology

7.1.1 Managing the Queue

Ombudsman Finding

The SCA's ability to manage its wait lists and to facilitate a case moving along the care continuum from the point of initial referral to first appointment with an oncologist lacks supportive and appropriate information technology.

The importance of technology in today's multifaceted health care system was succinctly addressed in 2006 by Dr. Brian Postl who was at the time the federal government's national advisor on wait times. Postl stated that, "...the importance of technology is its ability to allow health care

providers to share critical information easily and accurately. Accurate information is crucial if patients are to have a choice and receive the right care at the right time..."⁹⁵

The technology used to manage the wait lists impacts the SCA's ability to provide the "right care at the right time." For example, Ombudsman investigators were told that if three new patient appointment spots open up, no SCA staff could say, "these are the next three people on the wait list who need appointments" and know with certainty that those three individuals would be the ones who actually got the appointments.⁹⁶ Ombudsman Saskatchewan suspects that this is largely because the wait list is managed using computer programs plus a manual list which all contain the patients' information.

Recommendation 5

The SCA review and evaluate its information and communication technology on an ongoing basis or as needed to ensure the technology can adequately and effectively support the provision of cancer care services.

7.1.2 Data Gaps

Ombudsman Finding

The SCA's electronic medical records system only captures information internal to the Agency and is unable to capture and store information produced by external sources. This results in medical records that are a mixture of electronic and paper information.

A data gap occurs when the gathering, transfer, storage, retention, or retrieval of patient information negatively impacts the efficiency of the care continuum for the individual patient or group of patients. The SCA's wait list is a means by which the Agency gathers, stores, and retrieves pertinent patient information used to assess the urgency of care and the readiness of patients to receive care. Beyond the obvious clinical value of the patient information, the wait list is an administrative tool that the SCA uses to manage patient access to its services.

The word "list" is really a misnomer; the SCA's wait list at the time of this review is not one cohesive listing of patients, but a patchwork of patient information coming into the SCA at various entry points and in various formats, much of it in paper format. An added complication is that referring doctors and patients do not understand the Agency's referral and triage process (see Section 8.1.2). As a result, there are often data gaps in patient information which can affect the patient's transition through the wait list and can contribute to delay.

In addition, when capacity at either cancer centre is limited, patients are re-referred between the centres. At the time of our review, the computer systems between the centres did not “speak” to one another, resulting in a patient’s information having to be placed in paper form and manually transferred. This can also affect the patient’s transition through the wait lists and can contribute to delay.

Ombudsman Saskatchewan found that at the time of our review, the SCA was keeping its own medical file about each patient electronically. These internal electronic medical files included information from the PAC and other non-clinical staff, as well as clinical information. The electronic medical records are not complete, however, in the sense that they do not allow information that comes from external sources to be inputted. For example, there are often essential medical tests, such as CT scans, that are performed outside of the Agency which provide critical information for determining appropriate diagnoses and treatment options. At the time of our review, the SCA was not able to incorporate these test results and other information provided by doctors external to the Agency into the Agency’s medical records for patients.

The introduction of comprehensive electronic medical records (EMR) for cancer patients receiving care at the SCA that includes both internal and external information would address the concerns created by the paper-driven system. EMR would be accessible to both centres and would meet both clinical needs for patient information and the administrative use of the clinical information to better manage patients through the care continuum.

EMR forms the basis of a provincial e-health system as described by Commissioner Dagnone.⁹⁷ There are many benefits to

EMR, both from a clinical and administrative perspective. EMR can reduce medical errors and improve clinical decision-making as the doctor has all of the pertinent information about his or her patient available when needed.⁹⁸ Administratively, EMR can play a significant role in reducing wait times as they add to the efficiency of care coordination.⁹⁹

The introduction of EMR could form the basis of transforming the wait lists or as we call them, the “patchwork” that exists in the Agency, into a provincial cancer care patient wait list. The system is collecting information and some is being used to track clinical outcomes. A patient wait list is a list of patients waiting for a specific medical treatment or intervention, but depending on its parameters, has the ability to be so much more. The paper lists limit the Agency’s ability to gather, analyze, and compare a wide variety of information across the patient population that could assist the Agency with identifying organizational capacity issues and service demands.

Other wait time management tools can also be introduced by the SCA; however, it has been found by Dr. Postl that electronic health record infrastructure is a fundamental tool for the future development of wait time management tools.¹⁰⁰

Recommendation 6

The SCA consider introducing complete and comprehensive electronic medical records to form the basis for the provincial patient wait list.

7.2 Data Collection – Measuring the Time

7.2.1 Managing the Patient Relationship - When Will I Receive Care?

Ombudsman Finding

The limited technology and the Agency's historical record keeping practices have created a number of inefficiencies that have impacted the Agency's ability to effectively and efficiently manage, not only the wait list, but also the Agency's limited resources and ultimately, the services themselves.

At the time of our review, the SCA did not provide patients on the wait list with timeframes or estimates of when they may be seen by an oncologist. Ombudsman investigators were told by several SCA staff that the Agency did not provide estimates to patients because it could not, with any certainty, know if the estimate would be met. Staff stated that in their opinions, providing an inaccurate time estimate causes more anxiety and concern to the patient than if no estimate is provided.¹⁰²

Cancer care agencies in neighbouring provinces can and do provide estimated timeframes to patients.¹⁰³ When asked why other jurisdictions are able to provide an estimate when the SCA is not, Ombudsman

investigators were told that part of the problem in providing estimates is the

generic nature of the Agency's oncology practice. In larger provinces, oncologists often specialize in site-specific cancers. As a province with a relatively small population, Saskatchewan cannot support specialized oncology practice, so the Agency's medical oncologists are generalists, treating a wide range of cancers. The generalist approach to treatment makes it more difficult to estimate timeframes to access treatment. In addition, Agency staff stated that they are unable to know with any certainty when emergent and urgent cases will arise or if and when other cases will take priority – all of which affects the SCA's ability to provide time estimates.

Though the generalist nature of the Agency's oncology services may impact the SCA's ability to provide time estimates, it is the opinion of Ombudsman Saskatchewan that this is not the predominant reason. The SCA simply does not have the appropriate information and tracking technology to adequately measure the time it takes for patients to be seen.

When Ombudsman investigators spoke to staff about why the SCA does not provide estimates, we heard several explanations, some of which were contradictory. Some advised that historically the Agency's record keeping was poor and did not allow the Agency to uniformly measure and understand its referral patterns.¹⁰⁴ Others suggested that cancer rates and treatment are too complex to adequately track referral patterns and need for services. Other staff, however, advised that there are predictable patterns in referrals over time, including with emergent and urgent cases, and that

"You cannot manage what you cannot measure."¹⁰¹

the SCA should be able to measure and record those patterns.¹⁰⁵ The Agency's failure to do so was, in the opinion of some staff, a lost opportunity.¹⁰⁶ The tracking of referral patterns could assist the Agency in better directing its limited resources.

It should be noted that since our review began, the Agency has started tracking referral patterns and doing so has produced some positive results. For example, prior to our review, the oncologists who were on call would not make any new patient appointments for the week they were on-call, but would take the emergent and urgent cases that were referred as new patients during the on-call week.¹⁰⁷ We were advised that since the SCA began to track its referral patterns, it learned that the on-call oncologists were rarely getting the same number or more of emergent and urgent referrals during their on-call weeks than they would normally have booked new patients in a week.¹⁰⁸ For example, if most oncologists take four new patients a week, the on-call oncologists were frequently seeing fewer than four emergent or urgent referrals during their on-call weeks. With better information, the referral centres are now booking some regular new patient appointments for oncologists during their on-call weeks.¹⁰⁹

7.2.2 Understanding the Patient Load

During our review, Ombudsman Saskatchewan investigators also learned that until recently the SCA did not uniformly or consistently track the number of patients any one oncologist had on his or her caseload at any given time. Historically, the SCA only tracked the number of new patients that an oncologist saw annually, and did not include the number of ongoing patients already on the doctor's caseload.

The SCA also lacked a common policy or practice among its oncologists about how long after their cancer therapy was completed patients would be seen by an oncologist before their case was transferred back to their primary physicians.¹¹⁰ There appeared to be a variety of practices used, numbers of patients, and timelines for each separate oncologist. Ombudsman investigators were told that the SCA began to track the actual caseloads of its physicians within the last few years and is working on a policy regarding when patients should be released back into the community.¹¹¹ We acknowledge this work and applaud these initiatives.

Though the SCA may have been able to effectively measure and track clinical outcomes for patients, it appears to have been unable historically to effectively track and measure its resource utilization and ultimately, its capacity. This hampers its ability to effectively manage the limited resources it has and to respond to situations of resource shortages. Simply put, "you cannot manage what you cannot measure."¹¹² Since improved measurements are being gathered and kept, these should allow the Agency to better understand its capacity issues and, from a patient perspective, know how many patients are waiting, how many new patients are expected including emergent and urgent files, and how long a patient will have to wait to see an oncologist.

Recommendation 7

The SCA develop measurement tools that will assist it in tracking what patient-centred and system-centred factors influence timely and equitable access to care. Such measures should be able to provide the Agency with information to systemically manage its resources, and also to provide information to individual patients about where they are on the wait list and when they can reasonably expect to be seen by a medical oncologist.

However, the information provided is limited in that it does not provide actual wait times for an initial consult with an oncologist and the initiation of chemotherapy or actual wait times at the ABCC or the SCC. Information about wait times should be made public and should be as detailed as possible to allow patients the ability to make informed choices with their primary care physician about available treatment options, including the possibility of out-of-province care.

Recommendation 8

We support and repeat the recommendation made in an operational review conducted by RockBank Consulting in 2006: "Ensuring that the SCA web site has protocols, guidelines, resources and links needed to support patients and families along the full cancer journey."¹¹⁴

7.3 Wait Time Websites

Ombudsman Finding

The SCA website does not provide adequate information about the wait times for oncology services.

Saskatchewan, like other jurisdictions, has several websites that provide information to patients and to health care providers about wait times for particular medical services. The most well known example of a wait time website is likely the Saskatchewan Surgical Initiative (www.sasksurgery.ca). Wait time websites are designed to provide up-to-date information in sufficient detail to allow the patient, in conjunction with her health care provider, to make informed decisions about her care.

The SCA also publishes information about wait times for chemotherapy on its website.

7.4 Summary

Many of the findings and recommendations contained within this report may require supportive technology in order to be realized. The SCA's referral office and other staff involved in assisting patients who are waiting to see an oncologist need better technology to properly and efficiently do their jobs. In order to have one provincial wait list, the SCA staff need a functioning e-health system that will coordinate patients' medical records, allow patients and providers easy access to medical records, test results and other information, and allow access to that information in a much faster and easier manner.¹¹⁴ In order to

understand and manage its wait lists, the SCA needs to understand its capacity and its demand. Technological improvements would assist in all of these areas and in others.

Working on capacity, management of the wait lists, and information technology should assist the SCA in ensuring timely care for all patients. However, some patients will continue to experience problems if they are not well-informed and do not feel respected in the process. In the next section we will examine communication concerns within the SCA.

Section 8

Communication and Navigation Assistance

8.0 Effective Communication

The primary issue raised in the original 2009 complaint to Ombudsman Saskatchewan involved a lack of information and effective communication between the SCA and a patient waiting to access cancer treatment. Most troubling for this individual was the fact that although she repeatedly asked several Agency staff members (both clinical and administrative) when she could expect to be seen by an oncologist, no one could or would provide her with that information. Yet when she contacted cancer agencies in other jurisdictions they promptly provided her with a timeline as to when she would, if referred to them, be seen by an oncologist. She then contacted the Ministry of Health and they too could not provide information or assistance in understanding why no one in Saskatchewan could tell her when she would see an oncologist.

Effective communication is an essential skill in any service industry and one that is vital to ensuring fair and reasonable treatment. Effective communication is a cornerstone of a PFCC health system, especially in the principles of informative care and respectful care, as PFCC requires that patients be active participants on their medical care team and in all decisions made about their medical care. In order for patients and

their families to participate in health care decisions, they need to be fully informed about their illness and treatment options in a timely manner.

Effective communication serves another essential purpose for provincial health care services: it increases public confidence. There needs to be a clear system that is used consistently and communicated sufficiently to patients and other stakeholders. This is necessary so that everyone is confident that every patient of the SCA has an equal opportunity to be fairly assessed and placed on the wait list, depending only on the patient's situation and needs and not based on any prohibited reason for differential treatment.

We were told in interviews with patients and community advocates that they believed that in certain cases non-clinical factors, such as whether or not an individual made a complaint to the SCA, could influence where an individual was placed on the wait list. Some believed that those who complained appeared to be moved up on the list over those who did not complain; others believed that those who complained would not be moved up on the list as quickly as those who did not. This suggests that public confidence in the wait list is lacking, at least for some patients and community advocates.

Even more troubling, we heard in interviews from some staff at the SCA that they too believed that outside non-clinical factors could affect an individual's placement on

the wait list.¹¹⁵ Other staff interviewed did not share this sentiment. Though the Ombudsman investigators found no information that would suggest that the wait lists have been compromised in the manner suggested by some community members and some SCA staff, the fact that there are people in both the community and within the SCA who believe that the wait lists could be influenced by irrelevant factors is very troubling and points to the great need for better communication of the processes used to determine how patients access treatment.

8.1 Communication Between the SCA and Community Doctors

Ombudsman Finding

The SCA does not effectively communicate with community doctors about capacity and resource issues that can have an impact on cancer care from the point of referral.

We found communication and information sharing issues between the SCA and the broader health sector.

Other reports commissioned by the SCA have indicated that many community doctors are unclear about their role, the SCA's processes, what the SCA requires of them, and how to ensure good care for their patients. For example:

A clear plan of care for the patients needs to be developed and

communicated to the GP/Surgeon. The GP/Surgeon also needs to receive communication as to what it is that they are responsible for.¹¹⁶

Interactions with referring physicians also indicate that there is an absence of communication regarding referral guidelines, triage, handling of urgent patients, and access to discussions with oncologists regarding patient issues.¹¹⁷

A lack of clear communication can lead to additional work for Agency staff, as well as differences of opinion and misunderstandings that result in frustration for Agency staff, community doctors, and patients.

In a truly patient-centred system, the SCA and referring doctors should act in a highly collaborative manner to ensure that patient care is seamless, continuous, and convenient to the patient. This would require that all involved health care professionals and patients be given consistent information so that everyone understands what is happening, why it is happening, and what is expected of them along the treatment pathway. This is the basis of Commissioner Dagnone's attributes of coordinated and convenient care within a truly PFCC system. What is essential is that patients do not bear the burden of a lack of communication. After all, patients are the reason why both the SCA and community doctors are in business and the goal should be providing the best patient care.

In its report, RockBank Consulting recommended "[a] shift in care to the most appropriate provider, e.g. moving some care back to the community and to family physicians, partnering with other providers, such as advanced practice nurses and clinical associates."¹¹⁸ Community doctors may be in a position to assist the SCA, thereby lessening the burden on the SCA

and its staff. Partnering with community doctors for various purposes may be a consideration to be examined.

Recommendation 9

The SCA review RockBank Consulting's report and give consideration to implementing the noted recommendation, "A shift in care to the most appropriate provider, e.g. moving some care back to the community and to family physicians, partnering with other providers, such as advanced practice nurses and clinical associates."

8.1.1 Out-of-Province Treatment Options

Ombudsman Finding

The expectation of the SCA is that the community doctor will discuss all treatment options directly with the patient including the potential for treatment out-of-province. It is not clear, however, whether all community doctors understand this expectation or have adequate information about the SCA capacity to know when they should consider referring patients out-of-province.

Many out-of-province treatments are funded by the province. SCA staff interviewed stated that referring patients out-of-province was the responsibility of the community doctor.¹¹⁹ The expectation of the SCA is that the community doctor will discuss all

treatment options directly with the patient and that these options will include a referral to one of the SCA's cancer centres or out-of-province depending on the patient's needs and personal preference. It is not clear, however, whether all community doctors understand this expectation or have adequate information about the SCA capacity, which may influence whether or not they refer their patient out-of-province.

The SCA advised Ombudsman investigators that after losing an oncologist in December 2008, the Agency sent by fax a one-page letter to community doctors within the referral area. However, this letter was not sent until February of 2009. The letter advised that the SCA had lost a medical oncologist at the ABCC and stated, "we are offering patients who are an equi-distance from Regina as they are from Saskatoon, the option of being seen by an oncologist at the Saskatoon Cancer Centre."¹²⁰ It also invited questions via telephone.

If the letter provided by the SCA in February 2009 was received, read, and understood by every doctor in the community making referrals to the SCA, it did not provide clear information about the problems at the ABCC. It informed the community doctors that the ABCC had lost an oncologist and was experiencing longer waits than usual, but it did not go into the detail required for referring doctors to be able to determine if they should refer their patients to another cancer centre or out-of-province for treatment. The letter provided to doctors in the community was clearly sent because there was a decrease in capacity at the ABCC, but the letter does not advise community doctors of the extent of the problem, its impact on wait times, the possibility of referring out-of-province for treatment, or of the community doctor's responsibility to discuss out-of-province options with patients.

Recommendation 10

In situations where the SCA finds itself unable to adequately address the demand for its services, the Agency provide all referring community doctors sufficient information to allow the referring doctors and their patients to make informed decisions about alternative care plans at other cancer centres, including agencies outside the province.

8.1.2 Referrals and Triage

According to the report, *Improving Access to Cancer Care*, many community doctors indicated that they were unsure about the SCA's triage process, referral guidelines, and how urgent patients are handled.¹²¹ This can lead to improper referrals or incomplete referrals resulting in Agency staff having to seek out needed information and address inappropriate referrals. If community doctors are provided with a better understanding of the process and of the Agency's referral expectations, that will assist them in providing the Agency with appropriate and complete referrals, thus saving Agency resources.

Differences in referrals may also lead to other issues. For example, prior to our review the SCA tracked patients on the wait list by the date that the patient was referred to the SCA. This caused some confusion as different doctors would refer patients at different times in the care continuum. One doctor may refer a patient upon receipt of a confirmation of cancer from a biopsy or diagnostic mammogram. Another doctor may wait until the patient had been referred

for surgery as the primary treatment for the cancer. Yet another doctor may wait until the patient had received surgery before referring the patient. A fourth doctor may wait until the patient had recovered from surgery and was ready to be seen by an oncologist before referring the patient.

The timing of when a community doctor refers a patient primarily affects a patient's perception of the amount of time that she has waited for an appointment, even though all patients are truly waiting from the moment they know or suspect that they have cancer. A patient who was not referred until after she had healed from her surgery would need to be seen much sooner than a patient who had not yet had surgery. Since this review the SCA has begun to track patients who require adjuvant chemotherapy treatment by their definitive surgery date, regardless of when the patient was referred.¹²²

As stated in the *Improving Access to Cancer Care* report,

Frequently at various care intervals, staff and clinicians note that information provided to patients from their referring physician is inconsistent or non-existent. This leads to many questions from patients, inadequate work ups, confusion on the part of the patient, and increased anxiety.¹²³

While the reasons are not entirely clear as to why community doctors are not providing their patients' complete information, it would be of assistance to both the patient and the referring doctor if the SCA clearly laid out its processes, its criteria, and its expectations of community doctors and also provided appropriate assistance and guidance when required.¹²⁴

Recommendation 11

The SCA develop a plan for consultation and use that plan to consult with community doctors to determine what information is required to be exchanged between health care providers in order to facilitate referrals.

Recommendation 12

If it has not already done so, the SCA develop information for community doctors to provide to patients they are referring to the SCA. This should include information about the wait list and the expected time period an individual should remain on the wait list and when patients can be expected to be referred back for follow-up care with their community doctors.

proposed by PFCC is entirely different from historical doctor-patient relationships and requires a substantial shift toward better communication between health care providers and patients.

Ombudsman Saskatchewan recognizes that the SCA is working towards a PFCC system. The shift required, however, will be no small task. The traditional health care system hinged on individuals with clinical training making clinical decisions and telling patients what was needed, what would happen, and when it would happen. Informing patients and their support network (family, friends, and advocates) and including them as part of the decision-making did not traditionally occur; under a PFCC system it must not only occur, it is an essential element in a successful outcome.

8.2.1 Providing Patients an Estimated Timeframe to See an Oncologist

8.2 Communicating With Patients

Within a truly PFCC system, patients and their health care providers are partners in a collaborative team jointly making health care decisions. In order for patients to actively participate in decisions, they require information and assistance with the areas where they lack expertise.

Moreover, in order to provide patients with care that is respectful and comprehensive, providers need to be listening to and listening for all of the indicators of what the patients' needs are and how those needs can best be met. The relationship

Ombudsman Finding

At the time of our review, the SCA did not provide patients with an estimated timeframe of when they would be seen by an oncologist.

The majority of Agency staff interviewed told Ombudsman investigators that the Agency does not provide an estimated timeframe to patients of when they would see an oncologist because providing an incorrect timeframe can raise the level of anxiety for the patient and is "worse" than providing no estimate at all. The Ombudsman understands that some patients may require

and want more detail than other patients and that providing an incorrect estimate may indeed raise anxiety. However, in the Ombudsman's opinion, it is unreasonable and somewhat paternalistic to not provide this information to patients who request it. Any perceived risk of raising patient anxiety could be greatly minimized if a process was in place for the SCA to promptly advise the patient of any delay and the reason for the delay, and give the patient a new estimate that will be met.

During the course of this review, the SCA made changes to its practice and is now providing more information to patients, but patients were still not given any estimate of when they might get an appointment, or where they were on the wait list. If an individual asked "when will I be seen?" she was still told "we don't know."¹²⁵ The Ombudsman investigators were told, however, that the Agency could provide additional information without giving the exact timelines. For example, the cancer centres are often booking appointments at least four weeks in advance. With the exception of a few cancellation appointments that are made, if a patient were to call and ask when she could expect to be seen, the referral centre could tell her that since she does not have an appointment yet, she will not see an oncologist for at least four weeks. While this practice would be an improvement over not providing any information, it still does not go far enough down that PFCC road. Patients require information in order to make informed decisions about their treatment and otherwise about their life. The SCA's practice of not providing estimates is unfair, somewhat paternalistic, and not patient-centred.

Recommendation 13

When requested, the SCA provide estimates to patients of when they will be seen by a medical oncologist. If an estimate is unable to be met, the SCA should inform the patient, provide an explanation, and provide a new estimate.

8.3 Navigational Assistance

Many patients require information about the care pathway and how to navigate it. This information assists patients in making informed decisions about their health care and about their personal affairs. All patients are unique in their needs and as such, different patients will require different information of varying levels of complexity and at different times. One way for the SCA to endeavor to provide an individual patient with all the information she may need or want at the time she needs it is to provide the patient with a system navigator. At the very least, the SCA should build opportunities into the care pathway where additional navigational assistance can be provided by existing staff.

8.3.1 System Navigators

Ombudsman Finding

The Patient Access Coordinator's role at the time of this review was not sufficient to act as a system navigator while the patient is waiting for a first appointment with an oncologist.

System navigators are individuals who work within or with the health care system and who act as a "personal guide" to patients and their families. System navigators provide general support and assistance to patients, which may include providing information, answering questions, identifying options for treatment and other support services, and acting as an advocate for patients when necessary.¹²⁶ Although Commissioner Dagnone suggested that a truly PFCC system would not require system navigators since everyone employed in the health field would be a system navigator, we do not presently have a PFCC system.

Around 2006, the SCA added the position of Patient Access Coordinator (PAC) at the ABCC and the SCC. While this position appears to provide a valuable service to patients, the PAC is not a system navigator. The PAC is required to contact every person who has been referred to the Agency within five days of the referral.¹²⁷ The PAC provides the patient with information about the orientation sessions and other support programs that are available at the SCA. They are the contact person between the cancer centre and the patient until the patient has an appointment with an oncologist, should the patient have any questions or concerns. Since the complaint

of Mrs. X, the PAC also informs the patient that she is on a wait list, and she is also told how many others are on the wait list and on average, how many new patients are added to the list each month. Ombudsman investigators were also advised that the PAC was inquiring as to whether the patient would be willing to see an oncologist in the other cancer centre in the province if that meant that the patient could see an oncologist sooner.¹²⁸

The addition of the PACs has likely alleviated anxiety for some patients of the SCA. Though helpful, the PAC is not a true system navigator in that they cannot provide or assemble the detailed clinical information that some patients may seek and they are not an advocate for patients.

When it introduced the PAC positions, the SCA did not intend for them to act as patient advocates, to provide clinical information, or arrange for clinical services for the individual. Decisions about when a patient will be seen and where the patient falls on the wait list are made entirely within the referral centre – and the PAC does not work out of or directly with the referral centre. The PAC, as the contact person for the patient, is able to listen to a patient and can sometimes listen for changes to the patient's condition or symptoms, but this information still needs to go to the referral centre in order to have any impact on the patient's place on the wait list. For all of these reasons, the PAC is not a true system navigator.

There remain, however, a number of options for the SCA to provide navigational assistance to patients. One option is to make the PAC a true system navigator by providing the PAC with all of the information needed to help patients navigate the system. Another option is to provide navigational

assistance through other professionals already working at the cancer centres.

8.3.2 Building Navigational Assistance into the SCA

Ombudsman Finding

Patients learn at their first appointment with an oncologist that the SCA has assigned a care team to them.

A full care team is assigned to a patient, but only when the patient has her first appointment with an oncologist. Beyond the doctor, the care team of a patient includes a nurse, a social worker, and other staff. If patients were able to access these professionals for assistance earlier in the process, these professionals are all in a good position to act as system navigators and help patients through the waiting process. The SCA should consider introducing care teams at an earlier stage in the process.

There may also be other options. The SCA should explore means to provide additional navigational assistance to patients after they have been referred and while they are waiting for their first appointment with an oncologist.

Recommendation 14

The SCA ensure navigational assistance is in place to assist patients who are waiting for a first appointment with an oncologist.

8.4 In it Together – Partnerships Between the SCA and its Patients

Effective communication is an essential skill in any service industry, one that is vital to ensuring fair and reasonable treatment, and a cornerstone of a PFCC health system, especially in the principles of informative and respectful care. Effective communication is especially necessary because PFCC requires that patients be active participants on their medical care team and in all decisions made about their care. In our original 2009 complaint, Mrs. X complained not about the care that she received, but about her experience while waiting to access care. In particular, she felt she faced roadblocks when seeking information about timeframes and treatment options, which made Mrs. X feel like she was an outsider with respect to any treatment that she may access. Mrs. X did not feel as though she was a partner in her medical care or a part of the medical care team. In other words, Mrs. X did not receive true patient and family centred care during the time that she was waiting to access care.

PFCC places emphasis on collaboration between caregivers and patients and their families at all levels of care and in all health care settings. As such, it redefines the relationships within a health care setting. The traditional model of health care was primarily “designed around the people who deliver the care.”¹²⁹ PFCC shifts the focus of the system from the caregiver to the care recipient - the patient. PFCC not only promotes change in clinical care, but in all aspects of the health care system from the environment (i.e. how a waiting room is

designed), to the administration (i.e. board governance/patient advisory councils), to the delivery of clinical services (i.e. care plans, nurse managers).

The SCA administrative process to manage the wait list appears to have developed over time, and is primarily focused on the organizational needs of the Agency. Individual patients have no involvement or influence in any decisions about how their case is managed while on a wait list until they see an oncologist. As stated previously in this report, at the time of our review patients were not provided with adequate information about the wait list and their placement on the list. To the Ombudsman's knowledge, patients are not involved in the oversight or evaluation of the wait list process.

For the SCA to move firmly from its traditional roots to a PFCC system it needs to become patient-centred in all aspects of care, including how that care is organized, administered, and delivered. The SCA can begin this process by introducing a patient charter.

A patient charter is not a service guarantee, but a guideline to help staff to make decisions in accordance with PFCC principles. A patient charter would focus on defining core elements of patient-centred care such as timely and coordinated care, the right to be heard and listened to, the ability to play a central role throughout the care process, the right to designate family members and others as advocates and partners, and other attributes of a PFCC system.¹³⁰ Another potential mechanism is to solicit ongoing feedback and advice from patients and their families about broader program planning, policies, and service delivery. Patient advice could be incorporated in different ways, including through patient advisory groups, polling,

or other innovating means of hearing from and involving patients and citizens.

Recommendation 15

Working in partnership, the SCA, its patients and patient advocacy groups develop and introduce a patient charter based on the principles of PFCC.

8.5 Summary

Effective communication is a cornerstone of a PFCC health system. PFCC requires that patients be active participants in all decisions made about their medical care and be partners with the SCA staff. In order for patients and their families to participate in health care decisions, they need to be fully informed about their illness and treatment options, and in a timely manner. Effective communication must not only occur with patients, but also with referring community doctors. Once a patient has been referred to the SCA and is in the "system", additional navigational supports may be required.

PFCC, as articulated by Commissioner Dagnone, requires a culture within the health care system and the SCA that fosters partnerships amongst health care providers, patients, their families and the cancer care community. "An operative PFCC model" at the SCA "cannot be designed or implemented" unless the Agency is prepared for and committed to change across the organization.¹³¹ Change at the SCA and within the culture of the Agency has not always been easy as we will discuss in Section 9.

Section 9

A Change in the Organizational Environment

9.0 The Environment of the SCA

Concerns about the organizational culture or environment within the SCA have been long standing and highlighted in previous reports. In the *Improving Access to Cancer Care* report, the author outlined the following issues related to the Agency's culture:

- Low levels of trust amongst team members.
- Diminished capacity to problem solve between individuals.
- Communication that is unclear, conflict ridden and has many workarounds.
- A need for clarity of roles and responsibilities as well as how processes work or are going to work.¹³²

Cultural issues can at times spill over into the community and the Agency's relationship with the larger community as found by Dagnone (2009) who stated:

Some patients and system leaders also called to my attention instances of ineffective, strained relationships among clinical staff, management and health regions. Patients and families dealing with cancer should not have

the additional worries of disjointed care and dysfunctional professional relations among those coordinating and delivering their care.¹³³

Commissioner Dagnone also recognized the historical nature of many of the concerns and pointed out that the SCA had not, at the time of his report, implemented recommendations regarding cultural changes that were made in previous reports.¹³⁴ The organizational culture of the SCA requires a significant shift if the Agency is to successfully move to a Patient and Family Centred model of care.

During interviews with staff of the SCA for this report, Ombudsman investigators were also told about issues involving the organizational culture at the SCA.¹³⁵ Many of the concerns raised were similar to those raised in the previous reports; it was unclear to the Ombudsman investigators, however, whether these concerns had any impact on patients' access to services at the Agency. Additionally, since 2009, the SCA has undergone a number of changes, including changes in its management personnel. The Ombudsman is very hopeful that these changes will resolve many of the concerns raised by staff of the SCA and described in earlier reports.

Ombudsman Saskatchewan was able to identify one issue with respect to the environment that directly impacted on the Agency's ability to fully understand and address issues concerning the wait lists, the

management of the lists, and ultimately a patient's access to cancer treatment.

9.1 The Complexity of Accessing Care

Ombudsman Finding

The administrative process used by the SCA to manage patients' access to cancer care services is unduly complicated.

In the interviews with SCA staff, almost every person stated that the processes they follow to intake, prioritize, schedule, and manage patients for treatment are very complex and that the sheer complexity of it all acts as an impediment to change.¹³⁶ The Ombudsman would agree that many things about cancer care are or can be complex. The etiology of cancer is complex. Treatments for cancer are often highly complicated and every individual patient's reactions to those treatments will be different, which means that managing side effects of treatments can also be highly complex. Providing access to treatment however, should not be complex.

The issues that Ombudsman investigators were examining, specifically the processes used to ensure that patients referred to the SCA receive treatment in a timely way, need not be complex. It appears to the Ombudsman that to some extent, this thinking has become an impediment for change within the organization. There is a need to simplify the process and make it more accessible to patients, families, and other health care partners, including referring physicians.

From an administrative perspective, the complexity associated with managing access to care is related to the process followed and the Agency's management of that process. This includes, but is not restricted to, the lack of appropriate information technology and the way staff are assigned work within the process itself. We appreciate that the SCA is working to create a more streamlined system. The Ombudsman does have a concern, however, with using the solution of layering additional processes or review mechanisms on top of the existing processes, as that may actually lead staff and others to see a more complicated and difficult system than actually exists. The complexity is also exacerbated by the fact that at the time of our review there was no one person responsible for the wait lists.

Overall, the SCA needs to ensure that access to treatment is fair and equitable, and that the process to access treatment is not made so complicated that those who work within the system barely understand it and those who do not work within the system have little hope in understanding the process. If there are bottlenecks or other concerns with the process that are causing delay, the SCA needs to identify and resolve them. It is not sufficient to claim that it is all too complicated. In fact, it is the responsibility of those within the SCA to ensure that the process is not unduly complicated and to adequately communicate the process in an understandable form to everyone who needs to know the process.

Recommendation 17

The SCA review its administrative processes connected to the wait list on an ongoing basis, with the goal to streamline and simplify the processes.

9.2 Summary

Concerns about the environment within the SCA are longstanding and have been highlighted in previous reports commissioned by the Agency and most recently, in the *For the Patient's Sake* review. Although we recognize that the issues around organizational culture primarily affect services beyond the scope of our review, the Ombudsman agrees with the previous reports and their recommendations and found that problems still linger and may hamper the Agency's desire and ability to move to a patient and family centred system. In particular, if staff of the SCA believe that the problems surrounding accessing cancer services and treatment are so complex that there is no ability to create a better system, this is an environmental issue that can be resolved within the SCA.

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Section 10

Changes Made at the SCA Since this Review

10.0 Progress Since Our Review

We began our review of the SCA's wait list process in 2009, following the receipt of a complaint. As is our policy, we first investigated and dealt with the individual complaint. The individual case file was completed and resolved in 2010. We began our systemic investigation following resolution of the case file. The systemic review was time consuming and comprehensive as it required the investigators to fully understand the Agency's process and more specifically the etiology and treatment of breast cancer. The SCA has been fully cooperative with our review.

Our review is a point in time study that looked at the SCA's management of its wait lists from 2009 to 2010. The SCA took very seriously the concerns Mrs. X and made concerted efforts to change its internal processes and procedures and, consequently, to improve the experience of many women waiting for chemotherapy treatment. A number of these changes also coincided with our final report recommendations.

To a great extent the SCA is a different Agency today than the one Mrs. X encountered in 2009. The Agency has made significant changes to its administration, its technology, its processes

and its interaction with patients and their families.

10.1 What Changes has the SCA Made?

On May 30, 2011 the SCA and Ombudsman Saskatchewan met and the agency provided a summary of their progress to date. Since 2010 the SCA has made several changes to its leadership, its administration, its technology, and its processes. The Agency has made a concerted effort to become patient and family centred and has formed a Patient and Family Advisory Council that advises on various SCA matters. Other significant improvements include,

- As of May 2011, the Agency has a full complement of oncologists and hematologists.
- The Agency has undergone a LEAN exercise of its case management process, involving both staff and stakeholders.
- The Agency has developed multi-disciplinary tumour groups, which have adopted benchmarks for treatment and continue to look at improving access to care.
- The guidelines adopted by these multi-disciplinary tumour groups are

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- The Agency has developed multi-disciplinary tumour groups, which have adopted benchmarks for treatment and continue to look at improving access to care.
- The guidelines adopted by these multi-disciplinary tumour groups are

- posted on the SCA website as they are adopted.
- The Agency has set and publicly discussed five-year access targets:
 - 100% of patients contacted within 24 hours of referral;
 - 100% of patients screened for distress;
 - 100% of cases reviewed by a Multi-disciplinary team (MDT);
 - 100% of patients receive a detailed care plan;
 - 100% of patients assessed for clinical trial eligibility;
 - 90% of new patient referrals seen within 7 days of referral;
 - 90% of patients started on treatment within 14 days of being ready to treat;
 - 90% of patients treated according to published treatment guidelines; and
 - 15% of patients enrolled in a clinical trial.
 - The Agency will report on its progress in meeting the benchmarks for care in its annual reports and on its website.
 - The Agency has improved its electronic information technology, including enhancing its main computer system that it uses for electronic health records, scheduling, and wait lists. For example:
 - the system has been made more robust with additional information and fields having been included within the program;
 - the CMS system now allows the Agency to merge the two referral centre wait lists into one provincial list;
 - patient and wait list information can now be shared between centres and with health regions; and
 - health data and information from other health service providers can now be placed within the Agency's electronic medical records.
 - The Agency has strengthened its internal oversight over the wait lists and now provides to its senior leadership, Board, and stakeholders concise information about the wait lists and wait times across the province.
 - The Agency has drafted a discharge policy and is working on implementing that policy.
 - The Agency has developed a distress screening tool and does distress screens (through the PACs) on all new patients in order to better support patients and their families.
- Ombudsman Saskatchewan acknowledges the efforts and progress of the Agency. Most specifically we recognize the Agency's efforts to:
- include patients and their families in the design and development of SCA processes, policies, space, and environment.
 - introduce tumour groups and implement recognized benchmarks.
 - improve support for patients and families, including its use of a distress screening tool. This appears to be a useful tool for ensuring that new patients of the Agency are able to access all of the services offered by the SCA that can assist patients who are under stress or anxiety while waiting for treatment.

- provide time estimates for needed treatment to patients.

The changes that have been implemented by the SCA appear to be positive and will likely take it a significant distance towards the end goal of having all patients of the Agency receive accessible, timely, and appropriate treatment provided in a respectful manner. There is still work that the Agency will need to undertake, however, in order to fully meet all of the recommendations made in this report and to continue striving for quality improvement.

We began this review because the Agency at that time would not tell women when they would receive life-saving treatment. The Agency, to its credit, has changed that practice and is now providing estimates to patients who request this information. We understand, however, that the provision of this information is dependent on the number of patients already registered and waiting to receive treatment or what the Agency refers to as its "backlog". We have been told that any significant increase in the backlog would likely make it impossible for the SCA to provide estimates to patients. It is our hope that the Agency, as it continues to improve its processes, can find ways to provide estimates to any patient who requests that information now and in the future – no matter the backlog.

Endnotes

- 1 This report when we refer to both cancer centres run by the SCA, we refer to them as the "cancer centres."
- 2 Health Council of Canada (2007). *Wading through Wait Times: What Do Meaningful Reductions and Guarantees Mean?: An Update on Wait Times for Health Care*. Toronto: Health Council of Canada. Website: http://healthcouncilcanada.ca/en/index.php?page=shop.product_details&flypage=shop.flypage&product_id=18&category_id=8&manufacturer_id=0&option=com_virtuemart&Itemid=170 (Health Council of Canada, *Wading through Wait Times*). See also, B. Postl (2006). *Final Report of the Federal Advisor on Wait times*. Ottawa: Health Canada at 18. Website: <http://www.hc-sc.gc.ca/hcs-sss/pubs/system-regime/2006-wait-attente/index-eng.php> (Postl, *Final Report*).
- 3 Postl, *Final Report*, *Ibid*.
- 4 The Canadian Medical Protective Association (2007). *Wait Times: A Medical Liability Perspective*. Ottawa: The Canadian Medical Protective Association at 4. Website: http://www.cmq-acq.org/uploads/wait_times_2007_cmpa.pdf (CMPA, *Wait Times*).
- 5 Health Council of Canada. *Wading through Wait Times*, *supra* note 2, at 3.
- 6 *Ibid*.
- 7 Identifying information such as names and exact dates of treatment will not be used to protect the identity of the individual complainant.
- 8 CMPA, *Wait Times*, *supra* note 4, at 4.
- 9 According to the Canadian Cancer Society, breast cancer is the most commonly diagnosed cancer, excluding non-melanoma skin cancer, among women: Canadian Cancer Society website, http://www.cancer.ca/Saskatchewan/About%20cancer/Cancer%20statistics/Stats%20at%20a%20glance/Breast%20cancer.aspx?sc_lang=en&r=1, last updated May 19, 2010.
- 10 We are, without question, aware that men can also be diagnosed with breast cancer. We also recognize that the illness is far more prevalent in women: see for example the Canadian Cancer Society website, http://www.cancer.ca/Saskatchewan/About%20cancer/Cancer%20statistics/Stats%20at%20a%20glance/Breast%20cancer.aspx?sc_lang=en&r=1. For ease and convenience in this report, we will use feminine terms, but we intend the report and our discussion of services and improvements to apply equally to all patients referred to the SCA with breast cancer, regardless of gender.
- 11 See T. Dagnone (2009). *For Patients' Sake: Patient First Review Commissioner's Report to the Saskatchewan Minister of Health*. Website: <http://www.health.gov.sk.ca/patient-first-commissioners-report> (Dagnone, *For Patients' Sake*).
- 12 *Ibid*. at 13-14.
- 13 RockBank Consulting Ltd. (March 2006). *Saskatchewan Cancer Agency Clinical Service Directional Plan: Submission to Saskatchewan Health, the SCA, and the SCA Review Phase Two Steering Committee* (RockBank Consulting, *Clinical Service Directional Plan*).
- 14 S. Bazylewski (June 2007). *Improving Access to Cancer Care: Phase One Report*. Operational review prepared for Saskatchewan Health and the Saskatchewan Cancer Agency (Bazylewski, *Improving Access to Cancer Care*).
- 15 In completing this review we found many excellent sources of information for individuals who have been diagnosed with breast cancer and other forms of cancer, as well as information for their families. This section provides only general information, mainly retrieved from information produced by the Canadian Cancer Society and Statistics Canada (Health Reports). For more on breast cancer and treatment options, we encourage the reader to contact the Canadian Cancer Society or access its website at www.cancer.ca.
- 16 Canadian Cancer Society's Steering Committee (2010). *Canadian Cancer Statistics 2010*. Toronto: Canadian Cancer Society. Website: http://www.cancer.ca/canada-wide/about%20cancer/cancer%20statistics/~/_media/CCS/Canada%20wide/Files%20List/English%20files%20heading/pdf%20not%20in%20publications%20section/Canadian%20Cancer%20Statistics2020102020English.ashx.

- 17 The Ombudsman acknowledges that breast cancer also occurs among men, but at a much lower rate. According to D. Muir, R. Kanthan, and S.C. Kanthan (2003), male breast cancer occurs at a rate of 1% of their female counterparts: D. Muir, R. Kanthan, & S.C. Kanthan (2003), Male versus female breast cancers. A population-based comparative immunohistochemical analysis. *Archives of Pathology and Laboratory Medicine*. 127(1), 36-41. Website: <http://www.archivesofpathology.org/doi/abs/10.1043/0003-9985%282003%29127%3C36%3AMVFB%3E2.0.CO%3B2>.
- 18 L.F. Ellison & K. Wilkins (March 2009). Cancer prevalence in Canadian population. *Health Reports*. 20 (1), 1-14 at 1. Statistics Canada, Catalogue no. 82-003-XPE. Website: <http://www.statcan.gc.ca/pub/82-003-x/2009001/article/10800-eng.pdf>.
- 19 This section is not intended to provide detailed information about all available forms of breast cancer treatment. The information provided will be a general overview of the most common treatment options available for individuals diagnosed with breast cancer. The information is provided in order to offer common definitions of the many terms associated with these treatment options and to set the foundation to understand the clinical pathways involved in treatment.
- 20 Canadian Breast Cancer Network (June 2008). *Breast Cancer Wait Times in Canada: 2008 Report Card*. Ottawa: Canadian Breast Cancer Network at 6. Website: <http://64.26.166.131/en/?section=3&category=116&regionid=&page=12009> (CBCN, 2008 Report Card). See also A. Reed, R. Williams, P. Wall, & P. Hasselback (September/October 2004). Waiting Times for breast cancer treatment in Alberta. *Canadian Journal of Public Health*. 95 (5), 341-345. Website: journal.cpha.ca/index.php/cjph/article/download/540/540.
- 21 Depending on the type of cancer other forms of treatment also include hormonal therapy, biological therapy, or stem cell transplant. Source: Canadian Cancer Society website. *Treatment for breast cancer*. Retrieved March 16, 2010 from website: http://www.cancer.ca/Saskatchewan/About%20cancer/Types%20of%20cancer/Treatment%20for%20breast%20cancer.aspx?sc_lang=en&r=1.
- 22 *Ibid.*
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- 40 In the 2003 *First Ministers' Accord on Health Care Renewal*, the federal, provincial, and territorial First Ministers committed to timely access to health care services. In the 2004 *10-Year Plan to Strengthen Health Care*, they committed to achieve, by March 31, 2007, reductions in wait times in 5 priority areas including:
- Sight restoration (surgery to remove cataracts)
 - Diagnostic imaging (mammograms and cervical screening)
 - Cancer care (curative radiation therapy)
 - Cardiac care (coronary artery bypass graft)
 - Joint replacement (surgery to implant artificial hip and knee joints).
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- 42 Rayson, *et. al.*, *Comparison of Elapsed Times . . .*, *supra* note 25, at 328.
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- 45 Lohrisch, C., C. Paltiel, K. Gelmon, C. Speers, S. Taylor, J. Burnett, & I. Olivetto (October 2006). Impact on Survival of Time From Definitive Surgery to Initiation of Adjuvant Chemotherapy for Early Stage Breast Cancer. *Journal of Clinical Oncology*. 24 (30), 4888-4894. Website: <http://jco.ascopubs.org/content/24/30/4888.full.pdf+html> (Lohrisch, *et. al.*, Impact on survival of time . . .).
- 46 Lohrisch, *et. al.*, Impact on survival of time . . ., *Ibid.*, at 4893.
- 47 Rayson, *et al.*, *Comparison of Elapsed Times . . .*, *supra* note 25.
- 48 *Ibid.*
- 49 CBCN, 2008 *Report Card*, *supra* note 20, at 17.
- 50 For example, the SCA oversees the patient lodges in Regina and Saskatoon which provide affordable shelter for individuals who are getting cancer treatments and their companions. The SCA is also responsible for overseeing and monitoring cancer screening programs for colorectal, cervical, and breast cancer. Additionally, the SCA is responsible for the School of Radiation Therapy, a 25-month radiation therapist diploma program.
- 51 In actuality, each cancer centre has two separate wait lists, as there are separate lists at each centre for those patients who need to see a medical oncologist and those patients who need to see a radiation oncologist.
- 52 The SCA has the ability to merge the wait lists from each cancer centre to create a provincial list. Patients who have been referred and are waiting to access treatment will be offered the option of going to the other cancer centre in the province when the wait lists between the cancer centres become uneven, and the Operations Committee determines that this option is needed.
- 53 Though the wait lists queue all cancer patients, as we have already stated the Ombudsman's review focused only on patients with cancer in one particular site (the breast), of a specific nature (early stage, curative), and requiring a specific treatment pathway (surgery and adjuvant chemotherapy).
- 54 As stated in Section 1, we are aware that men can also be diagnosed with breast cancer. We also recognize that the illness is far more prevalent in women. For ease and convenience in this report, we will use feminine terms, but

we intend the report and our discussion of services and improvements to apply equally to all patients referred to the SCA with breast cancer, regardless of gender.

- 55 We will use the terms "doctor in the community" and "community doctor" interchangeably. Both refer to all doctors working outside of the Saskatchewan Cancer Agency and include family doctors or general practitioners, surgeons, and other specialists.
- 56 We will discuss referrals to other provinces further in Section 8, under "Out-of-Province Treatment Options". For now, it is sufficient to say that for seeing an oncologist and receiving standard treatments, Saskatchewan patients can be referred to any cancer centre in Canada and have the costs covered by the province. Some treatments and out-of-country referrals require prior approval from the Ministry of Health in order for the costs to be covered by the province.
- 57 This package includes information provided by the SCA, which is mailed by volunteers.
- 58 First contact is typically made either by telephone or through receipt of the informational package.
- 59 On a case by case basis and depending on case circumstances, however, there may be further contact between the patient and the PAC. There will always be further contact by the PAC when the patient initiates it.
- 60 This involves looking up the patient on one of the computer systems used by the SCA.
- 61 The clinical considerations and assessments that make up the triage process are performed at the same time as many of the administrative duties. While we recognize the concurrence of these different aspects of the job, we are only looking at the administrative duties and so we need to distinguish the duties for that purpose.
- 62 These appointments are expected to last an hour and are booked for an hour.
- 63 Information quoted from a SCA staff member, June 2011.
- 64 At the time of writing this report there were two nurses at each referral centre reviewing patient charts and performing the initial triage process.
- 65 The nurse, using the information provided on referral and her own clinical expertise, determines what type of doctor the patient needs to see:
- if the patient requires chemotherapy or other types of systemic treatments, then she needs to see a medical oncologist, or an oncologist who specializes in prescribing medications like chemotherapy medications;
 - if the patient requires radiation therapy or treatment, then she needs to see a radiation oncologist;
 - children with cancer need to see a pediatric oncologist; and
 - if the patient has a cancer involving her blood and she is referred to the SCC, then she needs to see a hematologist. There are no hematologists on staff at the ABCC, so all patients with blood cancers at the ABCC see a medical oncologist.
- 66 At the time of our review for medically triaging charts, the medical oncologists at the ABCC used a different process than the one used by the medical oncologists at the SCC.
- 67 These categories have to do with at what point in the process the patient receives their cancer treatment and are described as follows:
- a) Neoadjuvant Therapy - all patients who require radiation or chemotherapy treatment prior to receiving surgery as treatment for the cancer.
 - b) Curative Non-surgery - all patients who have types of cancer for which surgery is not an option and only radiation and or chemotherapy are treatment options, such as individuals with hematological (blood) cancers, head and neck cancers, cervical cancer, or brain cancer.
 - c) Adjuvant Therapy - all patients for whom surgery is the first form of treatment, to be followed with radiation and/or chemotherapy treatment.
 - d) Palliative or Metastatic Disease - involves patients whose cancer has spread or metastasized beyond the initial site of the cancer or whose cancer is so advanced or of such a high grade that they do not have a reasonable potential for curing the cancer.
- 68 According to the SCA, they now use the triaging process of the ABCC for medical oncology triage at both centres.
- 69 At the time of our review, we understood that the oncologists at SCC had specialized by site of cancer much more so than the medical oncologists at the ABCC. The nurse then assigned charts to the medical oncologists on the basis of the site of the cancer and the oncologists' expertise with that cancer site.
- 70 At the time of our review, the process for medically triaging patient's files for medical oncology in Saskatoon was the same process used for radiation oncology files in both Regina and Saskatoon.

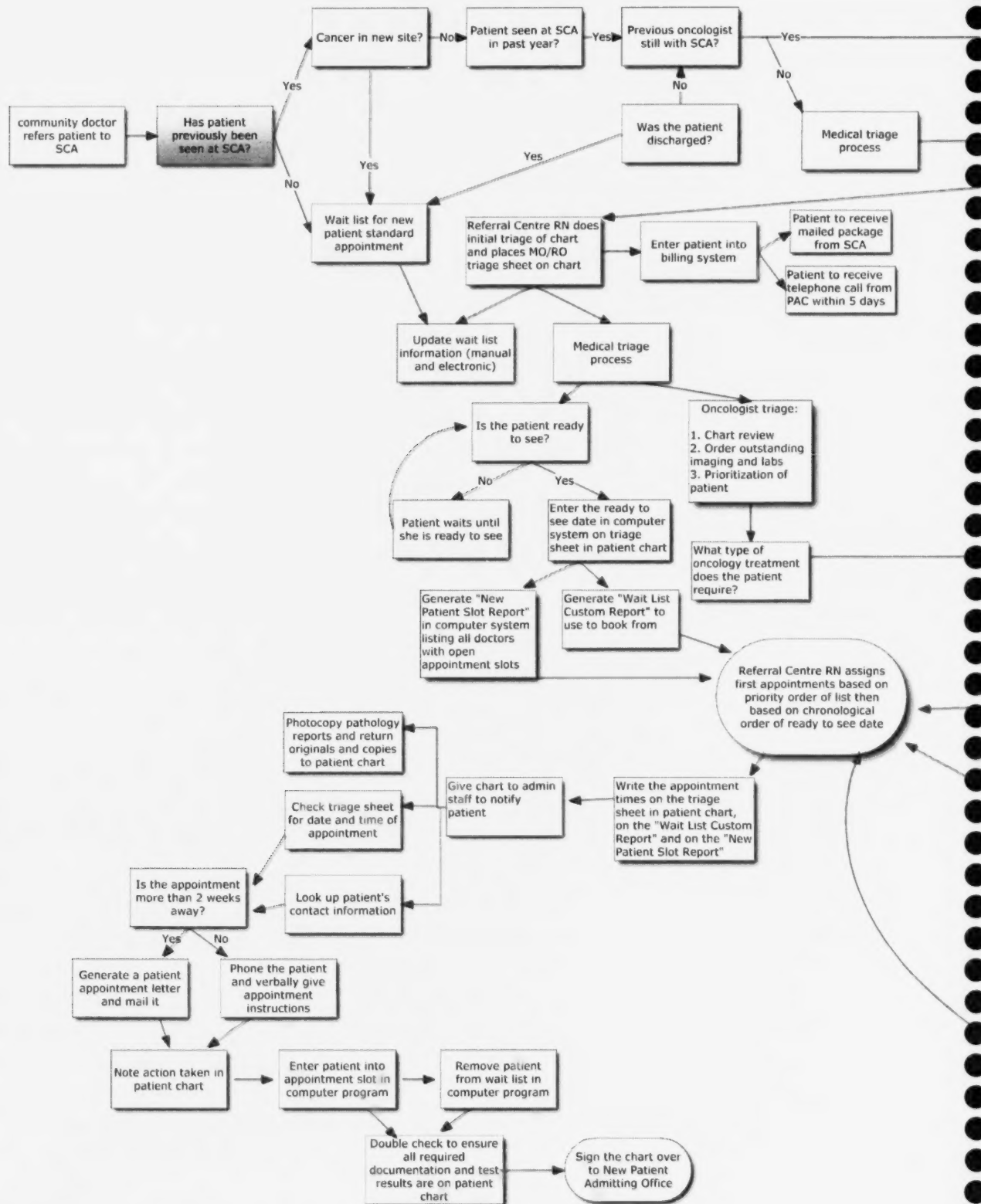
- 71 The SCA's process indicates that patients with breast cancer who do not receive surgery, but instead have a diagnostic biopsy, are of the same priority to begin chemotherapy within the twelve week informal benchmark as those who have had surgery. For the purposes of this report, we will focus on patients who had surgery as their first and primary form of treatment.
- 72 The Operations Committee at the SCA is made up of clinical staff and administrators of the SCA from a variety of disciplines.
- 73 We understand that during our review PACs began asking all patients during the first contact with the patient if they would consider going to the other cancer centre. If the patient requires assistance with the logistics, practical, or financial concerns about going to the other cancer centre, social work services are offered and provided to any patients who request them. Decision support is also offered and provided as required.
- 74 A note will be placed on the patient's chart to indicate that an offer to go to the other site was made and declined.
- 75 This is done on the same computer program on which the patient was initially searched to ascertain if the patient was previously a patient of the Agency.
- 76 The SCA reported in June 2011 that it is now providing estimates to patients of when they can expect to be seen. The SCA advises that its ability to provide estimates with any accuracy is dependent upon not having a long wait list and backlog. When the wait list gets to be long, then the ability of the Agency to estimate timeframes with accuracy is diminished.
- 77 When e-health is mentioned it is often referring to Electronic Medical Records that are stored in a way so that all health care providers in the province have access to the same electronic record of the patient's medical history. As Commissioner Dagnone stated, "The electronic health record is a series of information systems and technological infrastructure that, when integrated, will enable health care professionals to share patient information efficiently and securely." Dagnone, *For Patients' Sake*, supra note 11, at 42.
- 78 Postl, *Final Report*, supra note 2.
- 79 Interviews with SCA staff.
- 80 Interviews with SCA staff.
- 81 Interviews with SCA staff.
- 82 For example, in an article published on April 9, 2010 in *The Leader-Post* it described the story of a Regina doctor, Dr. Elizabeth Brydon, who made the difficult decision to close her gynecological oncology practice due to issues involving her working conditions. Gynecological oncologists do not work for the SCA or out of the SCA and Dr. Brydon's practice was a private practice.
- 83 Other non-clinical tasks required of referral centre nursing staff include: update a printed wait list (write the patient's name, chart number, and what service they are assigned to in the steno notebook) and "use a highlighter to identify patients added to the [wait] list since last printing."
- 84 Bazylewski, *Improving Access to Cancer Care*, supra note 14, at 16-17.
- 85 Bazylewski, *Improving Access to Cancer Care*, *Ibid.*, at 27.
- 86 Lohrisch, et al., *Impact on survival of time . . .*, supra note 45. For more information on benchmarks for breast cancer, please see Section 3.
- 87 On a monthly basis, the SCA collects information about people who are on the wait lists for each cancer centre and combines the information to create a "dashboard report." The dashboard report provides an overall picture of the wait list throughout the province. Staff from the SCA and the Ministry of Health then meet on a monthly basis to review the dashboard report to assess if the SCA is handling the wait lists appropriately.
- 88 More precisely, each cancer centre runs two wait lists: one list for patients who need to see a medical oncologist and one list for patients who need to see a radiation oncologist. Due to the issues under review, we are focusing on the lists for medical oncology or systemic treatment at each cancer centre.
- 89 Interviews with SCA staff.
- 90 Interviews with SCA staff. Ombudsman investigators asked why patients chose not to seek out the quickest treatment, but were informed by SCA staff that the SCA did not ask this question to patients who refused a re-referral. If re-referrals are offered to patients of the SCA again in the future, it may be useful for the SCA to collect this information.
- 91 Dagnone, *For Patients' Sake*, supra note 11, at 13.

- 92 Interviews with SCA staff. In June 2011, the SCA stated that this continues to be the case, as the Operations Committee of the Agency monitors the wait lists at the two centres and, when it sees inequity of access between the lists, offers are made to patients to go to the centre where they will be seen the quickest.
- 93 Postl, *Final Report*, *supra* note 2, at 38.
- 94 As we will review more fully in Section 10, since the time of our review the SCA has made its technology systems more robust and there is now the ability to link the two centres as well as allowing access to certain individuals outside of the SCA and allowing information to be inputted into the system.
- 95 Postl, *Final Report*, *supra* note 2, at 41.
- 96 Interviews with SCA staff.
- 97 Dagnone, *For Patients' Sake*, *supra* note 11, at 42.
- 98 Postl, *Final Report*, *supra* note 2.
- 99 Postl, *Final Report*, *Ibid.*, at 46.
- 100 Postl, *Final Report*, *supra* note 2, at 48.
- 101 Common business axiom.
- 102 Interviews with SCA staff.
- 103 In the complaint that came to our office, Mrs. X advised us that she had contacted Cancer Care Manitoba, as well as the Cross Cancer Institute in Edmonton and the Tom Baker Cancer Centre in Calgary, both of which operate through Alberta Health Services. These neighbouring cancer treatment providers were able to provide her with an estimate of when she would see an oncologist within 24 hours of her initial contact.
- 104 Interviews with SCA staff.
- 105 Interviews with SCA staff.
- 106 Interviews with SCA staff.
- 107 Interviews with SCA staff.
- 108 Interviews with SCA staff.
- 109 Interviews with SCA staff.
- 110 Interviews with SCA staff.
- 111 Interviews with SCA staff.
- 112 Common business axiom.
- 113 RockBank Consulting, *Clinical Service Directional Plan*, *supra* note 13, at 72.
- 114 Interviews with SCA staff.
- 115 In particular, we were advised that a physician working for the SCA would likely be seen sooner than others on the wait list with similar clinical needs. Their movement on the list would be based on their professional designation and association with the SCA. Source: interviews with SCA staff.
- 116 RockBank Consulting, *Clinical Service Directional Plan*, *supra* note 13, at 37.
- 117 Bazylewski, *Improving Access to Cancer Care*, *supra* note 14, at 13.
- 118 RockBank Consulting, *Clinical Service Directional Plan*, *supra* note 13, at 34.
- 119 Interviews with SCA staff.
- 120 SCA letter to community physicians, dated February 2009.
- 121 Bazylewski, *Improving Access to Cancer Care*, *supra* note 14, at 13.
- 122 Interviews with SCA staff.
- 123 Bazylewski, *Improving Access to Cancer Care*, *supra* note 14, at 20.
- 124 Although it does not have specific jurisdiction in this regard, the College of Physicians and Surgeons may be of assistance for consultations with or distributing information to physicians in the province. The College of Physicians

and Surgeons views part of its role to be improving the quality of health care generally through the province, and has facilitated in communications between physicians and health bodies, such as the SCA, in the past.

- 125 In May 2011, Ombudsman investigators were advised that the SCA will now provide estimates to patients who request them. We were advised, however, that estimates can only be provided when the wait list is not too long, and we were not given an indication of when the Agency considers the list to be "too long."
- 126 L. Pope (November 2003). *Report on health system navigator models prepared for: the Durham Haliburton Kawartha and Pine Ridge & the Simcoe York District Health Councils*. Website: <http://hdl.handle.net/1873/16070>. She states on page 2 that the goal of a system navigator is, "to enable the consumer and caregiver to make informed decisions about maintaining and improving their own health by providing thorough information with respect to their disease or disability and facilitating timely access..."
- 127 As described in Section 4.2.2 of this report.
- 128 Interviews with SCA staff.
- 129 Dagnone, *For Patients' Sake*, *supra* note 11, at 3.
- 130 S. Lewis (November 2009). *Making Patient-Centred Care Real: The Road to Implementation*. A Discussion Paper for the Saskatchewan Ministry of Health (draft 2.1) at 5. Website: <http://www.health.gov.sk.ca/patient-centred>.
- 131 P. Ponte-Reid, M. Conner, R. DeMarco, & J. Price (July-August 2004). Linking patient and family-centred care and patient safety: the next leap. *Nursing Economics*. 22 (4), 211-3, 215. Website: http://findarticles.com/p/articles/mi_m0FSW/is_4_22/ai_n17207345/.
- 132 Bazylewski, *Improving Access to Cancer Care*, *supra* note 14, at 13.
- 133 Dagnone, *For Patients' Sake*, *supra* note 11, at 24. This quote is taken from a discussion within the *For Patients' Sake* report in which issues experienced by cancer patients were raised to demonstrate a lack of coordinated care at the SCA. Commissioner Dagnone provided concrete examples of areas where a lack of coordination is evident: "Long clinic waits, limited community supports and delayed treatments are all signs of poor integration and coordination. Many people spoke of appointments not being coordinated and described communication gaps between clinical staff, health regions and the Cancer Agency. There is pressing need to work toward an integrated health record between the Cancer Agency and health regions."
- 134 As Dagnone (2009) stated at page 25 of his report, *For Patients Sake*: "An operational review of the Saskatchewan Cancer Agency, conducted in 2006, highlighted areas for improvement. For whatever reason, there is minimal evidence that progress has been made to address issues that affect the patients and the workforce. For example, a great deal can be done to standardize care in the Regina and Saskatoon clinics by adopting leading treatment protocols and care maps from other jurisdictions." *Supra* note 11.
- 135 For example, we heard about the concerns of some staff involving communication within the SCA and teamwork within the SCA. Source: interviews with SCA staff.
- 136 Interviews with SCA staff.

Appendix A



Review
appointment with
original oncologist

Wait list for new
patient - new to
provider
appointment

Palliative/Metastatic

Adjuvant Therapy

Curative Non-Surgery

Neoadjuvant Therapy

Oncologist's
judgment where the
patient fits in
priority

Oncologist
establishes priority
list

No

No

Is the site of cancer
breast?

Waiting more than
10 weeks since
surgery?

Yes

Highest priority

Capacity at referral
site?

Yes

No

Capacity at other SK
site?

Yes

NO

Social work services
offered

Will patient be seen
at other site?

Yes

No

Patient chart sent to
other site

Patient remains on
wait list at referral
site

Out-of-province
referral option
given to patient
and referring
physician

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